

UNIVERSITY OF CANTERBURY

The Experiences of Parents who have had a Stillborn Child in New Zealand

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of Master of Arts at the University of Canterbury.

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Dedication & Acknowledgements

I dedicate this thesis to my dad and step mum who gave birth to my little sister who was stillborn on 12/02/2002. She was a special little girl to our family and it has been a privilege to honour her memory with this research.

I also would like to acknowledge and offer my deepest gratitude to all of the parents who participated in this research. I am completely in awe of your generosity and courage to share some of your most painful and intimate experiences with me and for that I am truly grateful. Your stories will hopefully benefit other parents who have the unfortunate experience of giving birth to a stillborn baby.

I would also like to acknowledge my supervisors, Kate Reid and Sarah Whitcombe-dobbs, for all of their support, encouragement, time, dedication and guidance during this past year. Your expertise and wisdom has been truly valuable and without you I would never have crossed the finish line. Thank you, both.

Last but not least, thank you to all of my family and friends who have supported me throughout the last year. You have calmed me down and pushed me forward during the most stressful of times. Your belief in me kept me going when I sometimes didn't believe in myself.

Abstract

This research aimed to explore, understand, and describe the experiences of parents who have a stillborn child in New Zealand. Currently, there is limited stillbirth research being conducted in New Zealand and no research produced to date studying stillbirth from this perspective in New Zealand. Although there is similar international research it is important to understand the experience of having a stillbirth within the New Zealand context. Understanding the experience from a parent's perspective gives them a voice to share their story and highlight practices and procedures that were beneficial to their experience of stillbirth and those that were not.

Participants were recruited through a snowball technique and the research was conducted through a qualitative descriptive methodology. Semi structured interviews were conducted with eight participants (three male, five female) where they were asked to tell their story and share their experiences of having a stillbirth. The interviews were recorded and transcribed to conduct a thematic analysis. Through the thematic analysis six themes were found, each with further subthemes. The themes are: 'moving with the times,' 'the importance of staff,' 'the influence of society,' 'moving forward,' 'grief,' and 'the father's perspectives.'

This research aims to encourage further stillbirth research within New Zealand. Furthermore, the outcomes of this research will hopefully educate bureaucrats and healthcare professionals and have a positive influence on the care and support that parents of stillborn children receive.

Key to Extracts from Transcriptions

The following is the key to the abbreviations used within the transcripts and therefore also in the presentation of results.

[] Information added or used to clarify context or meaning

(...) Words, phrases or sentences edited out

Italics Participants' quoted interview

Chapter 1: Introduction

Introduction

The death of a loved one is classified as one of the most stressful life events that a person can experience. The array of emotional trauma and stress associated with losing a loved one can be further exaggerated with the loss of a child due to the often unexpected nature of the death (Rosenblatt, 2002). The perinatal mortality rate in New Zealand is 10 per 1000 births with approximately half attributed to stillbirths; the outcome of 5.1 of every 1000 births is a stillborn child (Perinatal and Maternal Mortality Review Committee, 2015). International literature suggests that parents who experience the tragedy of losing a child can encounter difficulties with healthcare staff, stigmatising social experiences, struggles with mental health, overwhelming grief, and underwhelming support both professionally and personally (Cacciatore, Froen, & Killian, 2013; Crawley & Jones-Brierley, 2013; Gold, 2007). There is little evidence in the New Zealand context of how well we are dealing with stillbirths and therefore, exploring, understanding, and describing the experience of parents' who have stillborn children in New Zealand is the priority for this study. This research aims to give parents of stillborn children a voice to share their experiences and perception of the care and support they receive from both healthcare professionals and family and friends. It aims to provide them with an opportunity to challenge and compliment current best practice models and highlight areas that may need improvement whilst recognising areas which are of a high standard. By respecting these experiences this research will contribute to the body of knowledge on stillbirths in New

Zealand to improve the services and care that parents receive from all healthcare professionals, and create awareness of the support and understanding that parents receive from family and friends after a stillbirth.

The Research Context

As recently as 100 years ago it was common to see stillbirth rates as high as 50 per 1000 births (Mcclure & Bhutta, 2014). Today, in high income countries these rates have, on average, dropped to five per 1000 births. It was the introduction of antenatal care, hospitalisation for delivery, and caesarean section for foetal distress between the 1930's and 1940's in high income countries that had the greatest impact on reducing the rates of stillbirth (Mcclure & Bhutta, 2014).

Throughout time there have been different methods of what is considered best practice to reduce negative outcomes for parents who have a stillborn child (Crawley, Lomax, & Ayers, 2013). Prior to the 1970's in Western countries it was considered best practice for the baby to be delivered and then taken away instantly (Crawley, Lomax, & Ayers, 2013). Parents were discouraged from seeing or spending time with the baby as it was believed that this would be too traumatic and would cause unwarranted emotional harm. Conversely, after the 1970's, parents were encouraged to embrace their infant and keep mementos as a means of closure (Crawley et al., 2013). However, in recent literature, there have been many opposing hypotheses with reference to seeing the child and creating mementos and the effect this practice has on parents. Some found unfavourable outcomes such as Post Traumatic Stress Disorder, partnership

breakdown, and worse overall mental health outcomes (Hughes, Turton, Hopper, & Evans, 2003; Turton, Hughes, Evans, & Fainman, 2001; Turton, Evans, & Hughes, 2009) whereas others have found favourable outcomes such as less depression and anxiety (Cacciatore & Bushfield, 2008; Rådestad, Steineck, Nordin, & Sjögren, 1996; Surkan, Rådestad, Cnattingius, Steineck, & Dickman, 2008). Therefore, it is important to consider not only what best practice is at the time of birth but what best practice is for the ongoing wellbeing of the parents. Wellbeing of the parents in this case is not just about their medical well being but should consist of a more holistic approach that includes their physical, mental, spiritual, social, and emotional wellbeing.

Stillbirth in New Zealand

In New Zealand, the most recent data available shows in 2013 the stillbirth rate was 5.1 per 1000 births a total of 307 stillbirths for that year. This is the lowest rate since 2007 when there was a stillbirth rate of 5.6 per 1000 births in 2010 (Perinatal and Maternal Mortality Review Committee, 2015). The stillbirth rate in New Zealand has shown a declining trend since 1996 when the stillbirth rate was 6.6 per 1000 births (Pink, 2006). Prior to 1996 the stillbirth rate was lower due to a change in definition. Between 1995 and 1996 the stillbirth rate in New Zealand almost doubled, from 190 stillbirths in 1995 to 330 stillbirths in 1996, simply a result of the new definition encompassing a wider range of perinatal deaths. Prior to September 1995 the definition for stillbirth was a child who was born dead after 28 weeks gestation, post September 1995 the definition for stillbirth changed to a baby born dead that weighs more than 400g or born after 20 weeks gestation (Pink, 2006). The change in definition increased the number of

stillbirths registered as more parents were eligible to register their baby's birth and death (Bascand, 2010). The stillbirth rates pre and post September 1995 cannot be compared due to the change in definition. Across the globe the definition of stillbirth differs and presents challenges in comparing stillbirth rates across countries, for example the definition for a stillbirth in the United Kingdom is a baby born dead after 24 weeks of completed pregnancy (National Health Service, 2015) and the World Health Organisation defines stillbirth as a baby born dead after 28 weeks of completed gestation (World Health Organisation, 2016). These definitions are just two examples of the range of stillbirth definitions worldwide, both of which are different to the New Zealand definition for stillbirth.

Whilst aiming to reduce the stillbirth rate further, it is now time for New Zealand to also concentrate on other areas surrounding stillbirths, namely, the care of families who go through the traumatic event of having a stillborn child. Exploring the experience of these parents and understanding their perception of the care they receive may contribute to improving the care offered at the time of stillbirth. This is the aim of this research.

Researcher Interest

My interest in the area of stillbirths has evolved from a personal experience I had as a young child. I was an eight year old girl and extremely excited about having a new baby sister or brother. However, in a turn of events, my father and stepmother went to the hospital only to find out that my baby sister, their child, was stillborn. My experience of stillbirth and the events that followed

are comparatively modern in contrast to many other experiences that I have read when considering this as a topic for research. My father and stepmother named, held, dressed, and took photos of their daughter. They invited me and my siblings up to the hospital to see and hold our baby sister for ourselves. Our journey did not end there; we were able to take my sister home in order to have a funeral/naming ceremony for her. At this time, we invited family and close friends to bear witness to her birth and death and grieve alongside us. It was an extremely difficult and sad time for our family and a time that I remember quite clearly. Every year on her birthday I think about her, how old she would be, what she might be like, and who she might look like. Our family has kept photos and mementos of her and it was these mementos that led me to my research topic.

The topic of stillbirth is greatly under-researched in New Zealand. This fuelled my interest in the topic and my particular interest in the after effects of stillbirth. I was interested in looking at the care that parents received from the very beginning of their stillbirth treatment, defined as, the exact time they found out their child was dead, to the very end, defined as, the point where those parents are now, as the death of a baby does not just end, it is carried for life, and the whole journey in-between. This includes the care, treatment, information, and support the parents received from health care professionals during their time in hospital; the time and experiences they shared with their child; and the care and support they received from family and friends at that time and to this day.

With some conflicting research on the best care of parents during this time, I am eager to explore and understand the experiences of parents who have stillborn children in New Zealand. I believe that their experiences and perspective on this issue may lead to better care for other parents of stillborn children in the future.

The Research Aim

The aim of this research is to explore, understand, and describe the experiences and give voice to parents who have stillborn children. A second aim of this study is to reveal specific challenges that men face when they have a stillborn child. Samuelson and colleagues (2001) suggest men often have considerably different experiences to their partner due to the indirect role they have in the hospital procedures (Samuelsson, Rådestad, & Segesten, 2001). The complexities of the grief that they face, their understanding of the process of events that unfold from the time doctors inform parents of the news that their baby has died to the point where they are today, and understanding the effect that this experience has had on their life and their worldview are of great interest.

There is conflicting evidence as to what best practice is concerning the care of parents who have stillborn children; gathering this data will provide an opportunity to understand what works well for parents, from the parents' point of view. It will be valuable in caring for parents who have stillborn children in future. With the data from these interviews, parents' individual experiences

will collectively provide common themes that may contribute to further research on specific ways to improve the experiences for parents who have stillborn children in New Zealand.

Research Approach

In order to hear the voice of the parents of children who are stillborn and explore, understand, and describe the experiences they had and the perception of their care a qualitative approach utilising semi structured interviews will be used. This approach will enable parents to tell the researcher their story in a conversational style that may allow them to feel more comfortable about sharing personal details from a sensitive time in their lives. This also gives the data authenticity and integrity as the information is coming straight from the parents reducing the possibility of bias. However, this method may also allow participants to amplify or reduce certain parts of their experience due the researcher's presence; participants may alter their story depending on what they think the researcher wants to hear. Another potential issue with this method is that without a specific set of questions to answer parents may overlook areas which may be of importance. On the other hand, a conversational approach may also allow parents to get side tracked and give the researcher more information than what they might have received if there was a specific set of questions. It is important to note that the experiences shared are the perceived reality of the parents. Although this experience may not be shared by someone from a different point of view, the perspective of the parents is the target for this research. Their perspective is of great value as it gives insight into what the

experience of stillbirth might be like for other parents in this situation. The data will be collated and analysed for themes which will allow the results to be shared and discussed widely.

Research Overview

This thesis has been divided into chapters: introduction, literature review, methodology and methods, the experiences, discussion, and conclusion. This introductory chapter is followed by a literature review that follows the changes and progressions of stillbirth throughout time and how the processes and practices, in terms of health care, have changed. It also reviews previous research in terms of the specific feelings and emotions that men have whilst going through the experience of having a stillborn child. Furthermore, it captures a small part of the research around the social experiences of parents who have stillborn children. The literature review is followed by the methodology and methods. The methodology is the theory on which the research is based and the method describes the practical approach to the research. The methodology and methods chapter will be followed by the experiences chapter which will include findings from this research and identification of themes. This chapter will also include a discussion of the themes with reference to previous literature. The discussion and conclusion chapter will follow and draw from the research results, analysis and discussion and propose recommendations and future research and how more research within New Zealand may inform healthcare practitioners supporting parents experiencing stillbirth, and how the research may increase awareness around the support that these parents need from family and friends.

Chapter 2: Literature Review

The Literature Search

An initial literature search was undertaken to understand the past and current perspectives on stillbirth. The literature was of both quantitative and qualitative methods and looked at the parent's perspective on their experience of stillbirth. Qualitative articles gave the most information surrounding this topic and focussed on the perspective of the parents and how they felt during and after their stillbirth.

Utilising the databases PsycInfo, Google Scholar, Medline OvidSP, and CINAHL the term 'stillbirth' was entered into the search engine. To streamline the search to my area of concern I focussed the search by adding defining phrases such as 'stigma', 'parent perspective', 'parent perception', 'men', 'New Zealand', 'coping', 'hospital', and 'healthcare' and ensuring all plurals and alternate phrases were included. The most successful of these phrases was 'men', 'coping', and 'hospital'. Literature was included if it: looked at support during and after stillbirth from both professionals and personal networks, care from healthcare professionals, mental health after stillbirth, both the mothers and fathers experience of stillbirth, and the history of stillbirth care throughout time, grieving and coping

As I progressed through the literature I noted specific words/phrases that helped to find further literature. These terms included 'stillbirth experiences' and 'stillbirth and support'.. Alongside these extra search terms, citations were examined to find further articles, thus producing a further list of sources to investigate.

Literature Review

Across the world the rate of stillbirths differ between high and low income countries. For low income countries it can be as high as 50 per 1000 births and for high income countries such as New Zealand it is approximately 5 per 1000 births (Mcclure & Bhutta, 2014).

The Lancet Stillbirth Series (Mcclure & Bhutta, 2014), is a six paper series which concentrates on many aspects of stillbirth. The series aims to prioritize stillbirth in the context of maternal, child and newborn survival with the overall goal of bringing together epidemiology, evidence for interventions, costing estimates and policy analysis to guide decision making and promote action with measurable change by 2020. This six paper series shows that stillbirths are still mostly unrecognised as a health problem unlike many other adverse pregnancy outcomes. Many low and middle income countries do not include stillbirth data in their vital statistics which adds to the challenge of evaluating stillbirths worldwide. Additionally, across high income countries there is no one set definition for stillbirth; in fact, across the world there are 35 different definitions for stillbirth which also adds to difficulties when evaluating stillbirths worldwide. Alongside this, stillbirths are unrecognised in any major global disease campaigns such as: the Millennium

Development Goals, Disability Adjusted Life Years, or Global Burden of Disease estimates (McClure & Bhutta, 2014).

In a systematic review of the literature surrounding stillbirth and healthcare professionals in high income, westernized countries, Ellis et al. (2016) looked at 4488 abstracts of which 52 were included in the study. Themes were extracted from the data and frequency effect sizes were calculated (FES). Themes were divided into five categories including: overarching themes, diagnosis, birth, post mortem, and follow up and support. Between these five theme groups there were 23 themes. The overarching themes included: behaviours and actions of staff can have a memorable impact on parents (53%), clear, easily understandable and structured information given sensitively at appropriate times, helps parents through their experience (45%), parents want privacy not abandonment (30%), research and multi professional training is important for all staff to improve standards of bereavement care (25%), parents wish for increased awareness and acknowledgement of stillbirth (20%), fathers may have different needs to mothers; they want to be involved in decision making and often focus on practical tasks (18%), continuity of care and carer is important to parents (15%), and parents with a baby who died in-utero may feel that their care is not appropriately prioritised by staff (5%). Many of these themes will be discussed below throughout this chapter.

The areas covered in this literature review include literature about care pre 1970's and post 1970's, impact of stillbirth on mental health, stigma and social experience, professional support, fathers perspective, and New Zealand research. The rationale for the two categories pre 1970's

and post 1970's is due to the change of care for parents of stillborn children over the 1970 period. Due to the changes in care we can expect changes in the experience that parents of stillborn children had. The other topics covered are informed and have been researched and discussed widely within the literature. All literature in this review come from international sources as there is very little research within New Zealand in this area.

Pre 1970's

Prior to the 1970's, it was seen internationally as best practice for the mother to give birth to the infant and then have the infant taken away immediately. It was believed that seeing the child would not be of any help to parents and that it would be too traumatic and would cause them to be unduly upset (Kirkley-Best & Kellner, 1982). Parents' grief was often seen as abnormal as others could not understand the attachment that existed between the parents and the stillborn child. It was thought that parents should be able to move on quickly as they barely knew their child. Until recently, society (inclusive of some medical practitioners) did not believe that parents should grieve for a stillbirth and parents' grief was therefore ignored and the birth of their dead baby treated as a 'non event' (Kirkley-Best & Kellner, 1982).

In a study by Bourne (1968), which aimed to discover the psychological effects of stillbirth on the mother and the family, they found a disturbing doctor-patient relationship. After sending out questionnaires to doctors and comparing information for 100 live births and 100 stillbirths it became increasingly obvious throughout the study that doctors of patients who have had a stillborn child showed reluctance to remember details about the about the patient and their care

(Bourne, 1968). Doctors who had to fill out questionnaires relating to a stillborn baby compared to a live born baby were more likely to need a prompt to return the questionnaire, more likely not to return the form at all, and more likely to respond to questions with the answer 'don't know' or leave the answer blank. Lovell (1983) interviewed both health professionals and mothers of stillborn children and found that healthcare professionals had a change in demeanor when it was understood that the baby had died and they treated the women as neither a mother nor a patient. Mothers of stillborn children were often sent home much earlier than those who had live births, were not checked up on as regularly as those who had live births, were put in rooms out of the way, and when they came in to contact with healthcare professionals they felt awkwardness in their contact and ultimately dismissed and avoided. Healthcare professionals who experience stillbirths may also feel upset or angry at the stillbirth. While parents may perceive this as them being dismissed it may be that the healthcare professional is also struggling with the death of the baby. For many healthcare professionals the loss of a patient and in particular the loss of a baby must be devastating.

On contrast to the above discussion, Lovell (1983) speaks of a 'hierarchy of sadness' where deaths at different stages of life are seen as more or less upsetting. Healthcare professionals seemed to deem stillbirths as lesser losses, lower on the hierarchy of sadness, and therefore, stillbirths were glossed over and the women who gave birth to stillborn babies were not treated as grieving mothers. Through the interviews with healthcare professionals Lovell (1983) found that healthcare professionals saw miscarriages as lesser losses than stillbirths and stillbirths lesser losses than babies who had lived for a short time. Babies who were deformed were also seen as

lesser losses and this perception was often relayed on to the mother who felt the baby's identity was then spoiled and her own identity as a mother deconstructed.

In a longitudinal study by Wolff, Nielson & Schiller (1970), mothers who had experienced stillbirth rated their doctors and nurses care for them. Over 50% of patients perceived their doctors care of them as cold or indifferent and over 60% of nurses were perceived in the same way. In similar research conducted by Rowe and colleagues (1978), 26 families who had experienced perinatal death participated in a retrospective study where they were interviewed by telephone ten to 22 months after the stillbirth. The majority of mothers indicated that they felt dissatisfied with the information they received about the stillbirth and dissatisfied, also, with the way in which the information was relayed to them (Rowe, Clyman, Green, Mikkelsen, Haight, & Ataide, 1978).

In a comprehensive study by Stringham & Riley (1982) they interviewed twenty women about giving birth and mourning a stillborn baby. There were 80 interview questions which covered a range of topics including: pregnancy and delivery, seeing and touching the baby, autopsy, burial, making memories, and mourning. Each woman in the study learned of the death of her baby differently. However, a significant portion of them were intensely fearful at the hospital procedures due to the lack of information, the long periods of silence, and a dearth of support from some healthcare professionals. When there is an unexpected death, such as a stillbirth, an autopsy becomes of greater importance. Pre 1970, it was common practice to perform an autopsy after an unexpected death and 75 percent of the participants in the research received autopsies. However, five participants felt they had to persevere to get the results of the autopsy,

whilst this is only a small proportion of the participants it does illustrate some of the difficulties parents of stillborn children face even when going through regular death procedures, such as an autopsy (Stringham & Riley, 1982).

Pre 1970 it was commonplace for the hospital to organise a burial or 'disposal of the remains', some participants were horrified to hear their newly born baby referred to as such. Of the families who did choose for the hospital to organise a burial rather than organise a burial themselves, they were greatly dissatisfied. The hospital did not inform some parents of the burial options and costs, they did not inform some of the parents where the baby was buried, there was no marker at some of the babies graves, and there was often no option to have a funeral or small service (Stringham & Riley, 1982).

Some of the most emotional answers were given in response to questions relating to seeing and holding the baby. Out of the twenty participants, eleven women could not recall any recommendation by medical professionals to see their baby, and they believed if they asked to see their baby they would face a negative reaction (Stringham & Riley, 1982). Only six of the women saw their baby and out of those six, five women saw and held their baby. Although it was not commonplace for parents to see and hold their baby pre 1970 it was somewhat common for parents to keep small tokens of their child in a small memory box. During the interviews several families shared some of the tokens they had kept of their baby. These tokens included hospital record, death certificate, autopsy report, newspaper announcement, photograph, and sympathy cards; these memory boxes seemed to aid the parent's grief and its resolution. This was a practice

that was initiated by parents themselves through their own need to mourn their baby as the support from healthcare professionals, family, and friends was often still lacking due to lack of understanding of the parents grief (Stringham & Riley, 1982).

Alongside the difficulty faced by healthcare practitioners in talking with parents who have had a stillborn child, comes the difficulty for family and friends to support the parents as well (Lewis, 1979; Stringham et al., 1982). Giving birth to a stillborn child can be an isolating event for parents, however, they can feel further isolated by family and friends who either avoid the topic in conversation or just avoid the parents as a whole (Lewis, 1979; Stringham et al., 1982). Parents reported many family and friends who were supportive of the parent's grief quickly became tired of it as they truly did not understand the emotion and pain behind the grief. Many women felt increasingly isolated as they felt that their grief was not socially acceptable and often faced unwelcome comments from family and friends such as 'You'll have another baby', 'You're lucky to be alive', or 'You never held him, were never a mother to him'. Whatever the aim of these comments were they were regarded as unhelpful and isolating by the mother as it felt like family and friends were trying to short circuit their grieving (Stringham & Riley, 1982).

O'Leary & Warland (2013) stated that whilst healthcare professionals at the time believed that they were doing what was in the best interest of the mother, the inability to meet, mourn, receive support, or participate in symbolic rituals for their stillborn child has caused many mothers a lifetime of grief. The authors interviewed older mothers about their experience of stillbirth between 50-70 years ago, and many still became upset at the thought of their lost child and felt

it was an important part of their lives despite it being, in some cases, unacknowledged. Stillbirth is no longer treated as a non event in westernised, high income countries (Radestad, Nordin, Steineck, & Sjogren, 1996). Along with helping women who experience stillbirth in today's world SANDS and other bereavement charities are often still contacted by women in their 60's and 70's who were prevented from seeing their baby. This was mainly due to the research and protocols at the time deeming that it was unhelpful for women to see their baby after it had died (Henley & Schott, 2008).

Post 1970's

Post 1970's, a change began to occur in the care given to families who had stillborn children. Many healthcare professionals better understand the risks and grief that parents of stillborn children experience and understand that every healthcare professional has one chance to give the best care and support possible for each individual set of parents' right (Downe, Schmidt, Kingdon, & Heazell, 2013). There is no one size fits all approach as every parent will grieve differently (Reynolds, 2003).

Parents of stillborn children face enduring and multiple losses (Downe et al., 2013). Many parents are now encouraged to see their baby as it is believed that this will facilitate recovery not only in terms of grief but also in terms of any psychological trauma that may occur (Crawley et al., 2013). However, today in the United Kingdom, not only are parents encouraged to see their baby but they are encouraged to hold them, bathe them, dress them, take photos of them, invite close

family to see them, have a funeral service for them, keep mementos of them such as a lock of hair or the blanket they were wrapped in, and even take them home (Crawley et al., 2013).

Whilst complete immersion into the stillborn child is an option for many parents it may not be their first instinct to meet their baby (Kingdon, O'Donnell, Givens, & Turner, 2015). Parents can feel fear at the thought of meeting their baby as they are unsure what the baby will look like. Whilst some stillborn babies do deteriorate and look different to a live baby, many stillborn babies look as if they are just sleeping live babies (Kingdon, O'Donnell, et al., 2015). In a metasynthesis of studies results showed that parents of stillborn children are more inclined to see their baby if the baby is described in a positive manner by healthcare professionals. This research also stated that whilst meeting the baby may not be the parent's first instinct the opportunity to do so is limited and although parents may decline to see their baby at first healthcare professionals should not treat this as closure to the topic. Further information and guidance for the parent's maybe necessary to calm the parent's worry and to reassure the parent's that it is a normal thing to do and will help them to create memories for the lifetime that they have lost with their child. Healthcare professionals should approach the topic sensitively each time the issue of meeting the baby is broached and offer different options that may make it easier for the parents to participate in memory making activities (Kingdon, O'Donnell, et al., 2015). Parents should not feel as if healthcare professionals are trying to pressure them or influence their decision. It should not be the aim of the healthcare professional to change the parent's decision but to inform the parents as much as possible so they can make the right decision for themselves in that moment and in the future. As mentioned earlier there is no one

size fits all approach; however, as long as healthcare professionals have informed parents of all of their options and let them know that they can change their decision and see the baby later then the decision to see and spend time with their baby should be completely up to the parents.

In the United Kingdom memory boxes are made up for parents that include items such as photos, hand and foot prints, a lock of hair, the clothes they wore, and any other significant items the baby came into contact with such as a toy or blanket (Kingdon, O'Donnell, et al., 2015). Although parents may refuse to meet their baby, healthcare professionals give parents these boxes so in future they still have the opportunity to know what their baby looked like and have items that show that their baby was real (Kingdon, et al., 2015). The benefit of collecting these tokens for the memory box is that parents get a second chance to know their baby and whilst it may not be the same as holding their baby in their arms, there is still the opportunity to know and possess special items relating to the baby. The memory box also gives parents choice, whilst they may have chosen not to meet their baby at the time of stillbirth, it allows parents the opportunity to choose when they are ready to know more about their baby. Schott & Henley (2007) suggested that taking away the parents ability to choose what they think is best may be damaging in itself; parents may be better able to cope when the decision is their own. There is no one size fits all approach to stillbirth and all parents will want and need different things post stillbirth (Henley & Schott, 2008; Reynolds, 2003).

An interpretive phenomenological analysis by Ryninks, Roberts-Collins, McKenzie-McHarg, & Horsch (2014) looked into the experience of women who met their stillborn child. They

interviewed women at three months post stillbirth and found that all women were happy with their decision to meet and spend time with their baby. The only regrets some of these women had about the time spent with their baby were they would have preferred to spend more time with their baby or engage in other rituals with their baby. Even when mothers expressed extreme distress during the contact with their baby they believed that the time spent with the baby was an important part of the process and in hindsight was the right decision for them. These findings were also supported by Kingdon, Givens, O'Donnell, & Turner (2015) in their qualitative systematic review of the clinical management and parental outcomes after stillbirth. In a study by Wilson, Boyle, & Ware (2015) meeting and holding the stillborn baby was associated with higher active grief (behaviours such as sadness, missing the baby, and crying for the baby) by mothers at six weeks, six months and 13 months but was not associated with an inability to cope or poor mental health. Although parents who saw and held their stillborn baby showed higher active grief there was no statistical difference in terms of mental health suggesting there may be other factors that contribute to poor mental health after a stillbirth. Ryninks et al. (2014) argue that a strong case can be made for the benefits of parents meeting their stillborn child. However, they ultimately conclude that engaging in discussions about the potential risks and benefits of meeting the baby and enabling parents to make their own informed choices is far better than blindly following perinatal bereavement protocols.

In contrast to Ryninks et al. (2014), findings from an online questionnaire showed that 'assumptive bonding' was helpful to women meeting their baby (Erlandsson, Warland, Cacciatore, & Radestad, 2013). Assumptive bonding is the assumption by healthcare

professionals that women giving birth to a stillborn baby would be no different from women giving birth to a live baby in wanting to meet their baby straight after birth. Mothers from this study said it felt natural and comfortable. Radestad & Christoffersen (2008) do not suggest assumptive bonding but do suggest that parents should meet their baby within the first 30 minutes after birth as this is when the baby is warm and a regular colour. In order for parents to meet their baby within the first 30 minutes of birth Radestad & Christoffersen (2008) suggest that women should not be asked if they want to meet their baby but how they would like to meet their baby. In their study of 20 families, some of the parents who were asked if they wanted to hold their baby initially did not want to do so and they later regretted not holding their baby while it was still warm. Parents who held their baby within the first 30 minutes of its birth said that this was the most valuable time that they spent with their baby.

Although it is well known that embracing the stillborn child can have positive effects for the parents as shown above, some recent literature highlights the potential for negative effects. Supporting parents by providing information, guidance, and offering a range of different options for parents to make their own decisions about meeting and caring for their baby during this time may be improve outcomes for parents of stillborn children. There is no one size fits all approach when caring for parents of stillborn children and giving the parents the ability to make their own informed choices about the way they would like to interact with their baby may help healthcare professionals tailor the care and support they give to each individual family.

Mental Health

A nationwide, population-based study in Sweden aimed to identify factors that would correlated with psychological symptoms in mothers who had a stillborn child. Participants were 314 mothers who had a stillbirth and 322 controls that had a live birth. Mothers who had a stillbirth and who had symptoms associated with anxiety or depression above the 90th percentile were studied. The measure for anxiety was the trait anxiety inventory. The trait anxiety inventory measures anxiety in adults on a four point scale with higher scores indicating higher anxiety levels. The trait anxiety inventory is commonly used in both research and clinical settings as there is substantial evidence supporting its reliability and validity (American Psychological Association, 2016). Results showed that 23 percent of women who had birth delayed more than 25 hours after the diagnosis of death had anxiety symptoms above the 90th percentile whereas only six percent women who gave birth within six hours of diagnosis of death had anxiety symptoms above the 90th percentile . Results also showed that 22 percent of women who had no token of remembrance of their child had anxiety symptoms above the 90th percentile whereas only seven percent of women who had a least one token of remembrance had anxiety related symptoms above the 90th percentile. Also, 19 percent of women who did not see their baby for as long as they had wished had anxiety scores above the 90th percentile (Rådestad et al., 1996). Whilst these are strong correlations it does not show causation and there may be a confounding factor that is influencing this correlation, such as mental health status prior to having a stillbirth. Surkan et al. (2008) used the same criteria as Radestad, Steineck, Nordin, & Sjogren (1996) in a Swedish based population study to asses care related factors that potentially led to greater depression in women who had stillborn children. Results

illustrated that mothers who showed symptoms of depression were more likely to do so if they did not get to spend as much time with their baby as they wanted. Thirty two percent of mothers who did not spend as much time with their baby as they wanted to showed increased depressive symptoms compared with only ten percent of women who spent as much time as they needed with their baby. While the lack of time spent with the baby correlated with increased symptoms of depression for mothers, some mothers who did get to spend as much time as they wanted with their baby some still had increased depressive symptoms, thus, suggesting that there are other factors involved in the rise of depressive symptoms.

Gold, Leon, Boggs, & Sen (2016) studied 377 bereaved mothers and 232 controls with live births in the United States of America in a longitudinal study. As a side note, excluding fathers from the study leads to the implicit assumption that mental health impacts will be more severe for mothers than for fathers. While this may be the case, without the research to support it, this remains an assumption. The 609 women surveyed provided self report data about depression and post traumatic stress disorder, demographics, pregnancy and loss experience, social support, and past and present mental health treatment, thus this study presents a more comprehensive view on mental health than the previous studies. They found a four-fold increased risk of depression and a seven-fold increased risk of post traumatic stress disorder in mothers of stillborn children and stated that these disorders remained persistent at nine months post birth. Two further studies (Vance et al., 1995 and Rådestad, 2001) supported Gold et al. (2016) each showing mothers still had elevated anxiety at 8 months and three years after

the stillbirth respectively compared to controls. Thus, these three studies give strong evidence for persistent mental health issues for mothers after giving birth to a stillborn baby.

Although research shows that parents never regret seeing or spending time with their child, there have been recent studies that show that seeing, holding, and caring for their baby can increase anxiety and depression during a subsequent pregnancy (Cacciatore, Rådestad, & Frøen, 2008). Depression and anxiety symptoms were measured using the 25-item Hopkins Symptom Check List (HSCL). The HSCL measures mental distress and is comprised of a 10-item anxiety subscale and a 15-item depression subscale. Responses to each item are coded on a 4-point scale with higher scores indicating higher mental distress. The HSCL has been used in research, medical trials, family practice, and with diverse cultural groups and consistently provides reliable and valid mental distress scores (Cacciatore et al., 2013). Whilst Cacciatore et al. (2008) found that seeing and holding the baby was related to lower scores of depression and anxiety in women who were not pregnant, it had the opposite effect on women who were progressing through a subsequent pregnancy, suggesting that during this time there is a temporary reverse in mental health. The study suggests that the change in mental health is temporary due to the lower scores of anxiety and depression in women who had already experienced a subsequent pregnancy. Women who had experienced a subsequent pregnancy at the time of the study may have showed lower scores of depression and anxiety because they had been through a second pregnancy and had a positive result. Mothers who were going through a subsequent pregnancy at the time of the research would most likely have had higher anxiety due to the fear of having another stillborn baby. An earlier study found similar results to Cacciatore et al. (2008), comparing women who did not see

their baby, women who did see their baby, and women who both saw and held their baby. Women who did not see their baby were the least likely to have depression, anxiety or symptoms of Post Traumatic Stress Disorder in a subsequent pregnancy. However, results for women who saw and held their baby and further embraced memory making and keeping mementoes were no worse off than other women who did not engage in these practices. Further successive steps of contact with the baby on top of seeing and holding were not predictive of increased symptoms of depression, anxiety, or post traumatic stress disorder in a subsequent pregnancy (Hughes et al., 2003). Hughes and colleagues (1999) also investigated time since stillbirth and the subsequent pregnancy and its relation to depression and anxiety. They found that women were at increased risk for depression and anxiety in a subsequent pregnancy but that risk was much higher for women who conceive within one year of their stillbirth. This may be due to the incomplete process of mourning; becoming pregnant whilst still grieving for a lost baby may intensify the parents' grieving and increase symptoms of anxiety and depression due to the constant reminder of their loss from their current pregnancy. O'Leary (2004) suggests that a subsequent pregnancy is a complex time for the mother. Being pregnant and anticipating a child is a wonderful and exciting time in a mother's life, however, the process of a repeat pregnancy can be a time of extreme anxiety that the same tragedy will reoccur. It can also be a constant reminder of potentially the most painful time in their life.

Depression and anxiety may come from seeing the baby as some literature suggest or from not seeing the baby as other literature suggests, there are discrepancies within the literature.

However, Cacciatore, Froen, & Killian (2013) suggest that depression and anxiety come from each individual situation and poor adjustment in bereavement. Variables such as age, time since stillbirth, education, and eagerness for the pregnancy correlated to raise or lower depression and anxiety scores. In the study they used the Hopkins Symptom Checklist (HSCL) as a measure of the mental health of 2,900 women who had stillbirths. The study controlled for variables such as: years since the stillbirth, the respondent's age at the time of the stillbirth, education, urbanicity, ethnicity, if they were victims of physical or psychological abuse during the pregnancy, whether the participant reported wanting the pregnancy that had resulted in the stillbirth, whether she reported being pregnant when the questionnaire was completed, residence in the United States, marital status, gestational age at the time of stillbirth, living arrangements during pregnancy, whether the stillbirth occurred during the third trimester, and whether the mother attended a prenatal care program or ultrasound screenings. Participants came from the United States of America, the United Kingdom, Canada, and Australia. Variables such as; being older at time of birth, having a higher level of education, being less excited about the pregnancy, and having more time since the stillbirth occurred were correlated with a decrease in scores for depression and anxiety (Cacciatore et al., 2013). Conversely, "blame" was significantly associated with higher rates of depression and anxiety. Women were first asked if they blamed anyone for the death of their baby and then were asked who that person was. The options for the answer were prenatal care provider, labour unit provider, father of the baby, myself, others, God, no blame, and do not know. Women who either blamed others or themselves had an increased likelihood of higher HSCL scores (indicating greater distress). Of the total sample 42.1 percent reported blaming at least one source for the stillbirth, out of those participants 24.6 percent of the women reported

self blaming, 25 percent reported blaming medical practitioners, and 11.1 percent blamed others. The women who blamed themselves were three times more likely to have increased HSCL scores; the women who blame medical practitioners were 1.5 times more likely to have elevated HSCL scores, and women who blamed others were 3.2 times more likely to have higher scores on the HSCL (Cacciatore et al., 2013). From the data presented in this study self blame could be considered more detrimental to mental wellbeing than blaming medical practitioners, however, self blame could be seen as equally detrimental to blaming others, however, the proportion of women who blame themselves is far greater than those who blame others. Blame is a significant issue for parents of stillborn babies as a high percentage of their deaths have an undetermined cause, even after postmortems. Cacciatore et al. (2013) believe blame; self blame in particular, to be the number one cause of poor adjustment in bereavement which leads to poor mental health outcomes in mothers after stillbirth. Whilst this study controlled for many variables, they did not control for mental health prior to stillbirth which could be a predictor of mental health after stillbirth.

In a qualitative survey of 162 women in the United Kingdom participants responded to a checklist of questions about memory making and sharing and also responded to five open ended questions. After a thematic analysis results showed that whilst some women had good experiences of support and care throughout their stillbirth many did not. Women reported feelings of isolation, exclusion and abandonment and results illustrated that these feelings can affect their identity as a patient, mother, and full citizen (Crawley & Jones-Brierley, 2013). They further studied the effect of this stigmatisation on women who had stillborn children and the

effect this had on women's mental health outcomes. Results showed that good mental health correlated positively with time since stillbirth but they also showed that better mental health was associated with the opportunity to share their memories that they had with their stillborn baby. For women who have stillborn children the chance to share their memories can be low as some people may undervalue their experience, misunderstand their grief, and can be unsure how to respond. For women who feel stigmatized by their friends, family, or community they can have more difficulty talking about and sharing their experience and therefore this may affect their mental health negatively. Therefore, in opposition to previous literature, it may be, that it is not accepting or refusing the opportunity to make memories that makes a difference in mental health it is the ability to talk openly about their experience and their story with those around them that makes the biggest difference in their mental health (Crawley, Lomax & Ayers, 2013).

Stigma and social experience

Some parents find it difficult to talk with professionals, family, and friends about their experiences. This can lead to feelings of stigma, isolation, shame, and guilt (Crawley & Jones-Brierley, 2013). In the United Kingdom analysis of 162 women's responses to open ended questions showed that stigma affected the perceived identity of the mother making them feel less of a patient, less of a mother and less of a citizen (Crawley & Jones-Brierley, 2013). Stigma was defined in terms of Goffman's Stigma Theory (1963). In hospital many medical staff treated women differently once it was realized that their child was dead, leading to feeling as though they were 'less of a patient'. Some mothers in the Crawley & Jones-Brierley study (2013) felt they were denied basic medical care, were left alone, not spoken to, not reassured about the process

they were going through, and in some cases denied pain relief. Aftercare was said to be inadequate and support services considerably lacking for several mothers. This recent finding aligns with findings from Wolf, Nielsen, & Schiller (1970). Surely, 40 years later the experiences of stillbirth and the care for the women who go through this tragedy should have improved. While stillbirths are declining in Western countries and healthcare professionals are dealing with stillbirth less than in previous years, the quality of care given to these families needs to be better than that which is stated above.

Alongside the stigma they felt as a patient, women in the Crawley & Jones-Brierley study (2013) also felt strong stigma as a mother of a stillborn child. Many people treated stillbirth as a 'non event', as if the stillbirth had never occurred, but how could a woman be a mother if there was no child? Mothers felt they were not allowed to grieve as stigma made them feel that the death of their child was not worthy of bereavement. Many mothers still chose not to see their child for their own personal reasons; however, those who did engage in memory making activities were inherently glad that they did so. They believed getting to know their baby, looking at every inch of its body, holding it and caressing it gave them their identity as a mother. Mothers who chose not to see their child regretted their decision later, firstly because they did not get to know their child and secondly because much of society belittled their experience and expected them to move on with life long before they were ready (Crawley & Jones-Brierley, 2013).

Lastly, stigma associated with having a stillbirth also disturbs the mothers identity as a full citizen (Crawley & Jones-Brierley, 2013). When using the term 'stigma', Goffman (1963) says it is "any

deeply discrediting attribute” which when attributed to a person spoils their social identity and leads to disqualification from full social acceptance (Goffman, 2009). Going by Goffman’s explanation, women who have a stillborn child face stigma that discredits them as a full citizen. Stigma that does this includes friends and family that avoid the mother in order to avoid conversation about the lost child, thus, constraining her social relationships and interactions (Crawley & Jones-Brierley, 2013). This reduces the amount of support she receives, and if the hypothesis of Crawley & Brierley-Jones (2013) is true; that it is the opportunity for women to share and talk openly about the experience they had with their child with others which determines the quality of their mental health, then stigma that discredits them as a full citizen and therefore reduces their support network will have a detrimental impact on the mental health of women who have stillbirths.

One study focused on the impact of perinatal death on family and social networks. Twenty parents completed a self administered questionnaire that was developed by the researchers. They found that many of the parents’ family and social networks were significantly reduced, and for some this was a permanent effect. Parents’ reported that many family and friends did not understand the grief of parents and expected them to move on quickly. Parents also noted that if they tried to talk about their baby or share their feelings people would look away and change the topic. When parents could maintain close ties with family and friends these relationships were especially nourishing and increased wellbeing and happiness (de Montigny, Beaudet, & Dumas, 1999). A study by Cacciatore and colleagues (2009) supported the notion that maintaining close ties with family and friends was good for the wellbeing of parents of stillborn

children. They collected data from 769 women using self report questionnaires online and their results showed that women who had social support from family and friends during the time after their stillbirth were far less likely to have symptoms of anxiety and depression. They also found that health care professionals and support groups were an important part of support after stillbirth in reducing depression and anxiety but support from these groups alone did not significantly reduce symptoms of anxiety and depression (Cacciatore, Schnebly, & Froen, 2009).

A study by Kavanaugh and colleagues (2004) delved into the concept of social support further by performing secondary analysis of two phenomenological studies of perinatal loss. Interviews from 22 mothers and nine fathers were included. They analysed all transcripts searching for statements that pertained to social support. Results showed that parents were supported in many ways including: emotional support, through giving advice and guidance, by financial and material support, through practical assistance, and through socializing. The most common of these social supports was emotional support which was explained as family and friends who were physically present, listened and gave the parents the opportunity to express their feelings, encouraged parents, and accepted the parent's feelings and sympathized with them. Support in the form of advice and guidance was often given by family or friends who had experienced their own perinatal loss. Parents often found this helpful; however, some advice and guidance could be unsupportive and generally came from people who did not understand the grief of losing a child. Financial or material support were objects such as cards books or flowers and parents said they found these nice gestures as it showed people were thinking of them and acknowledging their grief. Practical assistance was support in the form of helping with childcare or preparation

of meals; parents said friends and family who offer this support provide a lot of comfort. Socializing was named only by a few participants as a form of support but they believed their friends were being supportive when they encouraged them to socialize. These participants found socializing an important part of their healing process (Kavanaugh, Trier, & Korzec, 2004).

Professional Support

The nature of the interactions between healthcare professionals and parents of stillborn children play a large role in the parents' ability to cope with bereavement (Heazell et al., 2013). In a recent metasynthesis of 20 qualitative studies Lisy et al. (2016) explored the experiences of parents care at diagnosis of stillbirth, induction and birth, immediately post birth, and beyond. Behaviours that parents found helpful included a warm and sensitive communication style, clear and understandable information and repetition of information, shared decision making and inclusion of the father, and respect for individual needs and preferences. Guidance from health care professionals was useful when seeing and holding the baby, this included information from health care professionals on their baby's possible appearance, information on the possibility of spending time with their baby and what rituals this might include, and collection of memorabilia. After stillbirth, offers of follow-up care, including referrals for professional support, were appreciated. Each of these behaviours will be discussed below with reference to other literature.

The consensus from literature is that many families do not get enough support from healthcare professionals. One specific area which has received a significant amount of attention in regards

to the support parents received is the diagnosis of death for a stillborn baby. In a recent study retrospective study of 624 parents (599 women and 25 fathers) over 50 percent of the participants strongly agreed that the way in which the healthcare professional delivered the news that their baby was dead negatively influenced their grieving process. Participants were dichotomised into groups, those who strongly agreed that the death notification negatively influenced their grieving process and those who strongly disagreed that the death notification negatively influenced their grieving process. Between the two groups there were three common elements to the death notification: delay of news delivery, expression of sympathy, and communication of death. However, within these three common elements were clear distinctions between the two groups. For the group who believed that their grief was negatively influenced by the death notification the delay of news delivery was not only delayed due to regular hospital procedures such as waiting on healthcare professionals, moving exam rooms or to different facilities but also due to topic avoidance by healthcare professionals. Expression of sympathy also differed between the two groups; those who disagreed that the death notification negatively influenced their grieving shared many sympathies from healthcare professionals both verbal and nonverbal. Parents who believed they were negatively impacted by death notification only received verbal sympathies which were infrequent. Lastly, communication of death also differed between the two groups. Parents who reported the death notification negatively impacting their grief more frequently reported that health care professionals implied the diagnosis of the baby and parents had to infer the baby's death rather than being told directly (Pullen, Golden, & Cacciatore, 2012). The words used to tell parents that their child has died need to be carefully planned otherwise parents may feel as if the health care professional is de-personalizing and

minimizing the loss of their child (Cacciatore & Bushfield, 2008). The differences between the two groups are small but had a significant impact on the way parents perceived the care that they received during this time. One study explored the way in which women were told of their stillbirth, their results showed that women often face silence in the ultrasound room. Whilst there was often multiple healthcare professionals in the room nobody spoke and the mothers realized their baby was dead far sooner than when they were told by healthcare professionals which were often delayed some time. Whilst there may be reasons for this silence from the healthcare professionals perspective parents perceived this as a lack of care. The silence and perceived lack of care in this circumstance can cause further distress for mothers (Radestad, Malm, Lindgren, Pettersson, & Larsson, 2014). Whilst silence and subdued support may sometimes be helpful and potentially preferred as parents come to terms with information, there seems to be times where this is seen as unhelpful. This can then be perceived as poor communication and a lack of sympathy which can leave parents feeling angry and upset (Gold, 2007).

Another area where professional support plays a crucial role is the time between diagnosis of death and delivery of the baby (Trulsson & Rådestad, 2004). Although Malm et al. (2011) described this period of time as like 'waiting in no-mans-land' (p.52) where any sense of normality has disappeared, this period of time can be used constructively. During time parents can be given clear information, talked through the following processes, and visited by support services so parents have somebody to talk to once the baby is born (Erlandsson, Säflund, Wredling, & Rådestad, 2011). During this time healthcare professionals can be of great support to parents not

only by giving information but also by supporting them with their emotions, and listening if the parent is willing to talk. Often just being present can help parents to feel more at ease and cared for (Kavanaugh & Moro, 2006).

Trulsson & Rådestad (2004) completed a study that looked at the experience of twelve women with specific emphasis on the time between diagnosis of death and delivery. This time was an extremely difficult time as women were feeling a variety of emotions which made understanding and comprehending the information given to them difficult. Twenty five percent of the women in the study reported that they felt they were not given priority, the information they received was not sufficient, and the continuity of care was poor as they were seen by a multitude of different doctors, nurses, and midwives. Erlandsson and colleagues (2011) also explored the time between stillbirth diagnosis and birth through an internet questionnaire of 515 women. Through qualitative content analysis they found that whilst many mothers (70%) could cope and prepare themselves for the tough times to come other mothers (30%) could not and needed more support from health care staff. Mothers who felt they were not adequately cared for during this time experienced feelings of loneliness and abandonment, chaos, and severe anxiety (Erlandsson, Lindgren, Malm, Davidsson-Bremborg, & Radestad, 2011).

Another study also came to the conclusion that the length of time between diagnosis of death and delivery was important. After controlling for potentially confounding variables (age, education, relationship status, employment, and subsequent pregnancy), women who gave birth more than 24 hours after the diagnosis of death were five times more likely to have long term

anxiety related symptoms compared to those women who gave birth less than six hours after diagnosis of death. Women who gave birth between six and 24 hours after diagnosis of death were at intermediate risk of long term anxiety related symptoms (Rådestad et al., 1996). Trulsson & Rådestad (2004) suggest that the increase in anxiety related symptoms is due to the trauma of carrying a dead baby; they hypothesize that the trauma of carrying a dead baby may increase with duration. Their second hypothesis for this also may be that the increase in time between diagnosis of death and induction of labour increases the amount of opportunity for events to occur that may cause trauma. However, they suggest that the time between diagnosis of death and delivery should not be decreased to zero as many women indicated that the time in between was invaluable for processing information, preparing physically and psychologically for a vaginal delivery, resting before giving birth, and psychologically preparing for meeting and saying goodbye to their baby (Trulsson & Rådestad, 2004).

A study by Radestad and colleagues (2011) used mothers' gratefulness towards healthcare professionals as a way to evaluate the caring strategies. Behaviours that mothers were most grateful for were the collection of memories; the support to meet and hold their baby, the preservation of their motherhood, and the healthcare professional's engagement in their experience through support, information, and supervision (Radestad, Westerberg, Ekholm, Davidsson-Bremborg, & Erlandsson, 2011). Support during these times has also been illustrated as important by Saflund, Sjogren, & Wredling (2004) who also add that support during leaving the baby, organization and support for bereavement and care after leaving the hospital, and extra support in a subsequent pregnancy as important factors that should be managed by health care

professionals. These findings were also supported by Peters, Lisy, Riitano, Jordan, & Aromataris (2016) and Schott & Henley (2010).

The last stage at which health care professionals have contact with the parents is when parents separate from their child and leave the hospital. Not all parents leave the hospital without their baby, some take them home for funerals, but at some stage parents usually leave their baby in the arms of another caregiver and this is usually within the hospital setting (Lindgren, 2014). This is an unnatural occurrence and strips the parents of everything that they prepared for during the pregnancy (Lindgren, 2014). Lindgren (2014) completed a study that described mothers' experiences of the farewell of their child at their discharge from hospital. Twenty three mothers from Sweden were took part in semi structured interviews and through content analysis five themes were found. The first was the unnaturalness to leave the baby; leaving the child is abnormal and leaving them in a cold and dark autopsy room felt even worse. Going home empty handed was the second theme and parents found it unbearable to walk out the hospital doors with only their bags when they had expected to leave with their baby. Access to the child was the third theme and this was helpful to many parents who decided they would like to see their baby again after they had left the hospital, one couple from the study returned to the hospital every day for two weeks to see their baby. Security and insecurity in the separation was the fourth theme; parents felt better leaving their baby in the hands of somebody they knew such as the midwife, doctor, or nurse that had continually cared for them. This somewhat relieved the unnaturalness to leave their baby and made them feel secure that their baby would be safe and well looked after. Security also came from an understanding of what was going to happen to their

baby next. Parents who did not leave the child with a familiar person and who did not understand the next steps for the baby felt insecure in the separation. The last theme was letting go. Many women preferred to leave when their baby was still looking healthy. Women who stayed with their baby a long time after the birth noticed physical changes in the baby's body. In a short time parents seemed to need to both satisfy their biological need to care for the baby and say goodbye. Communication and information, continuity of care, and access to the child for as long as the parents needed, both after the birth and after they left the hospital gave parents greater security in leaving their baby behind. At a time when their identity as parents has been stripped from them, it is crucial that health care professionals can give parents any sense of security that they can offer (Lindgren, 2014).

Fathers' perspectives

The research surrounding stillbirth is primarily looking at consequences for the mother; fewer studies look at the effects having a stillborn baby has on his or her father. One of the aims for this study is to understand the process that fathers go through once finding out that their child has died. The fathers of today's generation are more likely to be actively involved in the preparation for their child's birth than fathers of previous generations (Badenhorst, Riches, Turton, & Hughes, 2006). Due to progress in science such as three dimensional scans, men can now feel closer than ever to their child whilst still in the womb. Men also get to know their child by listening to its heartbeat, feeling it kick through the mother's abdomen, and understanding its sleep schedules vicariously through the mother's sleep routines (McCreight, 2004; Weaver-Hightower, 2012). Fathers, together with their partner plan out their child's life. This might include its name, the

school it will attend, the sports it will play, the vacations they will have together, the rules and boundaries they will set, and the arguments they will have when it is a teenager (Weaver-Hightower, 2012). In a study by Wagner & Wallerstedt (1997) fathers were asked to score their grief at the time of the experience, 1 being no grief and 10 being severe grief. Fathers who suffered the stillbirth in the second trimester had a mean score of 10 and fathers who suffered the stillbirth in the third trimester had a mean score of 9.7. This shows the father's attachment to the baby is strong and may be just as strong as the mothers, however, from the studies published the emotional and physical process that the father progresses through is significantly different to the emotional and physical processes of the mother (Bonnette & Broom, 2012).

Over the years, in regards to stillbirth, it has been believed that the grief response of women is greater than the grief response of men (Stinson, Lasker, Lohmann, & Toedter, 1992). Stereotypical traits of men such as stoicism, strength, and being inexpressive may lead to the assumption that stillbirth affects women more than it affects men (Bonnette & Broom, 2012). One study showed men struggled with two motivations at the time of stillbirth: on the one hand they wanted to cope in a masculine way, but on the other hand they felt an intimate connection with their child. However, support of health care professionals, family and friends often indicated to fathers' that the mother's grief was more important and thus the father's grief was not perceived to be validated (Bonnette & Broom, 2012). In studies by Colon (2008), McCreight (2004) and Wagner & Wallerstedt (1997) fathers also felt that there was a difference in support given to the mother compared to themselves. They felt the mother received more support from friends, family, and the community and that they were disregarded.

Stage by stage, as the parents progress from the death notification through to giving birth through to meeting their baby and saying goodbye, fathers have a different experience to mothers as it is the mothers body carrying the child (Samuelsson et al., 2001). In a study by Samuelsson et al. (2001) eleven fathers were interviewed to understand how fathers felt when losing a child from intrauterine death. When fathers found out that their baby was dead they felt intense grief, meaninglessness, abandonment, emptiness, guilt, and fear of the abnormal. They felt an urgent need to get rid of the burden; they did not want their partners carrying a dead baby. The time between being told of the baby's death and delivery is a complicated time for fathers; they felt it was their job to take care of practical details and to protect their partner, but many found this frustrating as they were also emotionally distressed. Fathers also found this time important to prepare for the delivery. The delivery is another difficult time for fathers as focus is directly on the mother and baby. Fathers often felt frustrated and helpless in the situation but believed that the vaginal delivery felt more natural and conveyed more dignity. Some fathers also felt that they played an important supportive role to their partner during the delivery. After the baby was born some fathers found it natural to see and hold their baby, others did not, however, those who were encouraged to do so were glad they did. Fathers perceived the baby as warm and looking like it was just asleep; they spent their time with the baby remembering every aspect of their appearance: their complexion, their hair, their fingers and toes (Samuelsson et al., 2001). A small paragraph from Weaver-Hightower (2012) shows the complete love and adoration many fathers have for their child and their willingness to see and know as much as *possible about their baby*.

'I wish that I had seen her completely naked. That may sound strange or perverse, but I wanted to know all of her, every inch, every detail of this life we created. I never did look. I didn't have the courage or the foresight. Now, though, I want so much to see her knees and elbows, her tiny butt, the small of her back and curves of her armpits. I wish that I had been brave enough to pull open her eyelids to see her eyes (what color were they?). All these parts formed her, and I will never see them.' (p.470)

Concrete tokens of the baby such as a photograph, footprint, or a lock of hair were invaluable to the fathers and many believe that the hospitals should collect these for every stillborn child, even if the parents decline to take them (Samuelsson et al., 2001). On the return home fathers felt empty and cheated, the room that had been prepared for the baby felt like a slap in the face. Fathers' grief was aided by the concrete tokens of their child and support from hospital staff (Samuelsson et al., 2001). Another study delved deeper into this area and found that not only were fathers grateful for the help from health care professionals in creating memories with their baby but they were grateful when their baby was treated with respect just as a live newborn would be. Fathers were also aided by healthcare staff that validated their fatherhood and their grief as the father (Cacciatore, Erlandsson, & Radestad, 2013).

Samuelsson et al. (2001) also explored the differences in coping between mothers and fathers. Although some fathers did not feel like talking to others they still felt that it was their job to handle practical details and shield their partner from the outside world; many found this difficult

as their grief took up so much of their energy. Fathers' recognized a difference in grieving between them and their partners but also realized that their main support in getting through everyday life was their partner. Mothers needed to talk about their experiences and feelings whereas fathers were more silent in their grief. Fathers also felt that mothers had more people to talk to about their grief as mothers talked to coworkers and friends whereas, although fathers coworkers and friends offered indirect indications of consideration and respect through gestures, they did not often communicate about the stillbirth or the fathers grief. This suggests if fathers had a friend or family member they felt comfortable talking to they not be so silent in their grieving. The differences in dealing with their grief often caused misunderstandings between the parents and this is why fathers insisted that a mutual respect for each other's grief was of the highest importance and allowing each other to grieve in their own way helped in moving forward and feeling better faster (Samuelsson et al., 2001; Schott & Henley, 2010). Cacciatore and colleagues (2008) found that couples who recognized and respected the differences in each other's grieving styles reported more strength and cohesion as a couple (Cacciatore, DeFrain, Jones, & Jones, 2008). A possibility may be that the differences between couples may have little to do with the gender distinction but more to do with each individuals grieving and coping style.

A study by McGreal and colleagues (1997) adds to the literature further stating that after a stillbirth the relationship between the mother and the father can be put at risk by different types and different rates of grieving which can create barriers between the couple and thus reducing communication and increasing vulnerability (McGreal, Evans, & Burrows, 1997). Avelin, Radestad, Saflund, Wredling, & Erlandsson (2013) and Wallerstedt & Higgins (1996) both agree with

Mcgreal et al. (1997) as they found that parents expectations and expressions of grief could threaten their relationship, however, outcomes for each individual couple differ and relationships can also be strengthened by overcoming the challenges that the parents endure. Several other studies have studied relationship breakdown after a stillbirth and found that there are increased rates of separation and divorce for couples who experience having a stillborn child (Gold, Sen, & Hayward, 2010; Najman et al., 1993; Turton, Evans, & Hughes, 2009).

Often, families, friends and other support systems fail to legitimize the grief of parents to a stillborn child and they treat the death as a non event, therefore, it is important that parents legitimize each other's loss which will enable parents to communicate openly about their feelings. Experiencing different types of grief at different times and different rates is quite normal as people grieve differently (Mcgreal et al., 1997). Males are said to move through mourning phases faster than women but in many cases this can set instability in the partnership. Mcgreal et al. (1997) suggests that the reason that women take longer in their grief process is due to the blame that they put on themselves and the guilt that they feel for disappointing their partner and themselves in not doing what women are essentially made to do, carry a child and give birth, women often fail to communicate this guilt with their partners. Fathers on the other hand suffer shock, emptiness, anger, and helplessness but guilt does not feature as a component to their grief (Badenhorst et al., 2006).

In a study of the different coping strategies that mothers and fathers use Mcgreal et al. (1997) used a self report inventory, the Coping Scale for Adults, to investigate. They found that mothers

were more likely to use social support than fathers and were also more likely to use a range of coping techniques. Fathers were more likely to try ignoring the problem than mothers were. In a study by Erlandsson et al. (2011) questionnaires were sent out to 55 parents aiming to assess parents support after a stillbirth over a two year period. They deemed that the support strategies of many men and women were actually very similar. There were some slight differences, such as the professional support that the father found most helpful came from the counselor where the mother found the midwife more helpful. Also, while the top three supports for mothers and fathers were the same they were arranged differently. For mothers the top support was her other children, second was a new baby, and third was her partner; whereas for fathers the top support was their partner, second was their other children, and third was a new baby (Erlandsson, Säflund, et al., 2011).

In terms of mental health, much of the literature says that men suffer less psychological distress in terms of depression and anxiety, however if researchers measure alcohol use in their research then the gender differences in mental health status disappear (Vance, Boyle, Najman, & Thearle, 1995). Another area that has been explored with reference to men's mental health after stillbirth is the pregnancy after still birth. In a community-based cohort of 38 couples and matched controls Turton et al. (2011) explained that during the subsequent pregnancy fathers had increased anxiety and Post Traumatic Stress Disorder, however, once the baby was born alive their symptoms passed. Men, alongside women, also report physical reactions to the grief such as headaches, shivering, tiredness, and sleep disturbances (Aho, Tarkka, Astedt-Kurki, & Kaunonen, 2006). Some men go as far to inflict severe pain on themselves through intense

physical activity or tattooing (Aho et al., 2006). As mentioned above, men are less likely than women to talk about their grief and are more likely to grieve silently and alone (Weaver-Hightower, 2012). However, men reported that having a relationship with a man whom they could openly talk to had a positive impact on their grieving (Weaver-Hightower, 2012). Men who did not have another man to talk to missed that kind of relationship, this is a continual theme throughout the stillbirth experience as men also reported that not having another man to talk to between the death notification and delivery was also difficult (Samuelsson et al., 2001). Men are more likely to try and keep busy and show more anger and aggression in their grief (McCreight, 2004).

New Zealand research

The New Zealand guidelines for the management of stillbirth, which are determined by the Perinatal Society of Australia and New Zealand, recommends that parents be informed of their options to spend time and create memories with their baby, and that staff should offer to assist parents in these processes (Cunningham, 2012). Currently the only research done in New Zealand studying the subject of stillbirth looks at risk factors for having a stillborn child (Stacey et al., 2011). Alongside the investigation of the male perspective of having a stillborn child in New Zealand the current study will also look at the overall process that parents go through when having a stillborn child in New Zealand. The current study will be aiming to understand the perception of the care that parents in New Zealand experience from healthcare practitioners once they have been given the news that their child is dead. It will also be looking to understand the experience of support after stillbirth from family, friends, and personal communities in New

Zealand by looking at the perceived support that parents believed they received or did not receive from family and friends.

Conclusion

In a systematic review of the literature surrounding stillbirth a multitude of international articles were found that give insight into the challenges that parents of stillborn children face. Literature on stillbirth covers a wide range of perspectives looking at the variety of experiences and outcomes of these parents. Over time practice has changed aiming to provide better care for these parents; however it is still debated as to what the best practice is and how it is possible to improve the experiences and outcome for these parents.

All of the articles within this literature review are from Western countries other than New Zealand as there currently are no articles looking at the experiences or outcomes of parents of stillborn children in New Zealand. Due to the variety of experiences and outcomes of these parents shown in the literature it is important to understand what the experience of stillbirth might be like in the New Zealand context. It is important to understand aspects of care that parents see as important and helpful and aspects that parents see as unhelpful or need improvement. This study aims to understand the experience of parents of stillborn children and give these parents a voice to share what they believe is important in caring for parents of stillborn children. The following chapter will describe the methodology and method of the research.

Chapter 3: Methodology & Method

Methodology

Qualitative research

The aim of this study is to explore, understand and describe the perspective of parents who have stillborn children in New Zealand and to give them a voice. The best way to understand the perspective of a group of people is to talk to that group of people. Therefore a qualitative method was an appropriate framework for this research. A qualitative method allows for greater depth and openness in the research as it is not constricted by predetermined categories (Patton, 2002). Alongside this, qualitative encounters also give a breadth of information as participants stories are not only told with specific relevance to their own lives but with relation to cultural, historical and social context (Sandelowski, 1997). As this topic has not been studied within a New Zealand context a qualitative approach also makes no assumptions about the findings unlike the methods of a quantitative approach and therefore ensures that key issues are not overlooked. The stories and experiences that will be shared and collected in this research process will be situated within a cultural, social and historical context which will allow greater depth and breadth of understanding of the issues surrounding the experience that parents of stillborn children have in New Zealand.

The qualitative method allows for semi structured interviews which gives the participant the freedom to share as much or as little information with which they feel comfortable. It allows the researcher to not only receive the information that they need but also rewards them with additional information that can give extra meaning and allow further understanding of the main issue and perhaps secondary issues also. Becker (1996) states that taking the point of view of another is one of the advantages of qualitative study, however if we speak for others without truly understanding their perspective then we are disrespecting the people that we study. Therefore, we must allow participants the opportunity to truly express their perspective otherwise, we as researchers, may express their perspective wrongly and attribute feelings that we think they would feel in their circumstances (Blumer, 1969). Methodologies that include semi structured or unstructured interviews give the participant the opportunity to express their perspective as freely as possible which then gives the researcher the ability to report that perspective as accurately as possible (Blumer, 1969).

Qualitative Description

Sandelowski (1997) states 'The goal of qualitative inquiry is not the mere accumulation of information, but rather the transformation of understanding' (p.128). By gaining multiple perspectives on the stillbirth researchers and healthcare practitioners have more information which can transform previous ideas into new understandings. From this transformation of ideas they are able to understand issues better and use that understanding to create more beneficial healthcare surrounding stillbirth. Sandelowski (2000) also states that qualitative

descriptive studies entail 'the presentation of the facts of the case in everyday language,' (p.336) this is unlike other methods of qualitative research as they involve more use of the researcher's own interpretation. Qualitative descriptive researchers stay closer to the surface of their data ensuring descriptive validity; this means to portray the experience of the participant in a way that both the researcher and the participant would agree is accurate (Sandelowski, 2000). In order to portray the true perspective of the participants of this study, qualitative descriptive is an appropriate method as it allows the participants' voices and experiences to be heard directly as the researcher heard them with limited researcher bias. The disadvantage to using a qualitative descriptive method is that latent themes are unlikely to be picked up.

Neergaard and colleagues (2009), describe qualitative descriptive research as being 'a useful method for many research questions in healthcare because it can help to focus on the experiences of patients, relatives and professionals and their views on the patient-professional interaction and the organisation of the health care system' (Neergaard, Olesen, Andersen, & Sondergaard, 2009, p.55). This suits the current research well as it focuses on the experience of the patient and this includes their experience with healthcare professionals within the healthcare system. In order to achieve this breadth of information, researchers must be open to all data from participants as this gives a more detailed description of the experience (Sandelowski, 2000) and will provide a 'rich, straight description of an experience or event' (p.53) which Neergaard et al. (2009) states is distinctive of a qualitative descriptive study.

Philosophical Orientation

Qualitative descriptive studies are pragmatic in their design. This pragmatic approach has often been mistaken for as a design that is too simple and lacking rigour, however, the approach of a qualitative descriptive study has its own advantages (Neergaard et al., 2009). Although it is the least theoretical of approaches to research, this does not have to be seen as a negative, qualitative description allows for a more naturalistic enquiry. This means that phenomena are studied in the way that they naturally occur; no pre selection or manipulation of variables and no commitment to a theoretical framework (Sandelowski, 2000). These attributes lend themselves to the current research as they allow for greater breadth and depth of data to be gathered. By having no predetermined variables and no theoretical framework to control the process the researcher has the freedom to follow the data in whatever direction it goes and therefore has more opportunity to uncover insights that have not been understood before. This is beneficial to uncovering new information that encourages transformation of knowledge. The pragmatic approach of qualitative description is the research design for the current study and ensures the voices of the participants are heard and their experiences are portrayed authentically.

Rigour and Credibility

Table 1: Strategies to enhance rigour in QD

Strategy	Techniques
Authenticity	<p>The informants are free to speak</p> <p>Purposeful, flexible sampling</p> <p>Participant-driven data collection</p> <p>The informants' voices are heard</p> <p>Promoting richness rather than superficiality of data</p> <p>Conducting focus group interviews to diminish the role of the researcher</p> <p>Informants' perceptions are accurately represented</p> <p>Accurate transcription</p> <p>Content analysis (ensuring data-driven coding and categorizing)</p>
Credibility	<p>Capturing and portraying a truly insider perspective</p>
Criticality	<p>Reflection on the critical appraisal applied to every research decision</p>
Integrity	<p>Reflecting on researcher bias</p> <p>Dual role (clinician/researcher/interviewer) during the interview</p> <p>Dual role in the process of analysing</p> <p>Informants' validations/member checking</p> <p>Peer review/researcher triangulation</p>

(Neergaard et al., 2009, p.55)

Credibility and authenticity go hand in hand, to have a credible study it must study what it intended to and this means the data and the method in capturing the data must be authentic (Milne & Oberle, 2005). To have authentic data in this study, data will be collected through one on one interviews with parents who had had a still born child. The major techniques for an authentic study (from table 1) will all be captured in this study. Participants will have the opportunity to speak freely during their interview; semi structured interviewing allows the researcher to capture the participants story without researcher bias, participants can tell their story and share as much as they feel comfortable to share. Participants will be interviewed one on one rather than in focus groups due to the sensitive nature of the topic. Also, the aim of this research is to understand and explore each individual person's story and experience to gain a greater understanding and conducting focus group interviews would diminish the individual perspective and may encourage oversimplification of this distinct group of people's experience. Semi structured interviewing allows the researcher to probe for more information or ask for clarification when necessary but otherwise the data collection will be participant driven. The probes for further information and further clarification will give the data richness as the understanding of the phenomena can be deeper. Once the data has been gathered the data will be transcribed by the researcher just as the stories are told, this will capture the moments of silence, the laughter, and the use of slang and language of today's culture which will give the researcher the ability to provide readers with deeper meaning and the ability to show the essence of the stories that are told (Milne & Oberle, 2005; Neergaard et al., 2009). Participants will also be offered the opportunity to read over their transcript, which will ensure the validity

of the interview and that the researcher has truly understood what the participant said and expressed. Doing this is another step to ensure authenticity and credibility.

Just as credibility and authenticity go hand in hand, criticality and integrity also do. As mentioned in table one criticality is the reflection on critical appraisal. This means being critical of all decisions that are made during the research process, for the current research the decisions made are to ensure the voice of the participant is authentic and will keep researcher bias to a minimum. Criticality of all decisions and processes means the research is done to the highest standard and will have the greatest impact possible. Processes such as ensuring the participants can speak freely, purposeful and flexible sampling, and participant driven data collection will not only keep the data authentic but add to the integrity of the study. Alongside this, the researcher also understands and has made clear her own involvement with the topic of stillbirth, understanding her own perspective allows her to control her own biases and prevent them affecting the research. It is important to understand any potential researcher biases, being the main researcher means she controls all interviews, data analysis and ultimately the outcome of this research. Minimising researcher bias gives the research greater integrity (Milne & Oberle, 2005; Neergaard et al., 2009).

Analysis of Data

Transcription

A naturalistic approach will be taken by the researcher to transcribe the audio recordings. This means that the researcher will transcribe relaxed and cultural use of language, pauses and hesitations, and laughter that is essential to the capturing the essence of the interview and enables the researcher to recognize the emotion and sentiment within the transcription. Using a naturalistic approach to transcription maintains the participant's voice and gives the data further authenticity (Kelly, 2013). Keeping the participants' stories untouched ensures that the interview remains from the perspective of the participant and not the researcher.

Self transcription enables the researcher to become immersed within the stories of the participants. It allows the researcher to be placed back to the time of the interview for each participant and remember, feel, and hear the emotion, perspective, and meaning of each participant's story. Self transcribing means the researcher is able to ensure that the interview remains in the participant's words and captures the essence of the interview. Revisiting the recordings through transcription gives the researcher the opportunity for deeper comprehension and understanding of the stories and experiences (Braun & Clarke, 2006).

Data Analysis

Human science research aims to expose the meaning of human experience through comprehensive descriptions and accurate accounts of the experience (Moustakas, 1994). To do

this the use of thematic analysis will be employed. Braun & Clarke (2006) state that 'thematic analysis provides a flexible and useful research tool, which can potentially provide a rich and detailed, yet complex account of data,' (p.82) which is the aim of this analysis.

Once the interviews have been transcribed the process of analysis will start. Thematic analysis will be used to identify themes throughout the data. Due to the researcher transcribing all of the interviews herself, she will be partially immersed within the data already, continuing this immersion in the data, all transcripts will be reread before grouping together any commonalities between the data. Once the data has been read through again the process of identifying common elements between the transcripts will begin. This will lead to the grouping of common phenomena and the development of overall themes. The data will be re-examined multiple times throughout the analysis process to ensure all themes are identified. In thematic analysis, themes are identified from the data rather than being pre set from literature and found within the data (Payne, 2007). This ensures that the participants stories are used honestly and are not altered to fit categories that have been predetermined. From the data analysis major themes will be identified from all the participants' interviews. These will explained in chapter four.

Ethical considerations

Ethical Challenges

Due to the sensitive nature of the phenomenon being studied there are many ethical challenges that face this research. The first ethical challenge is the emotional distress that the interviews may cause. Whilst it can be therapeutic to talk about traumatic events it also can revive some grief. Being very aware of this ethical issue the researcher is prepared with tools to help the participants through the interview, these include: giving the participants as much time as they need to tell their story and express their emotion, if the participant is struggling the audio recorder can be switched off and they will be given a break, and if they feel they cannot continue they will be offered the chance to reschedule the interview or to withdraw from the research. The researcher also has the contact information for support services if the participants need or want it. The length and the potential intrusiveness of the interview is also ethical issue as it may cause emotional distress (Kelly, 2013). However, the length and intrusiveness of the interview is somewhat controlled by the participants as the longer they speak the longer the interview will be. If the participant is too distressed or feels uncomfortable it is likely that the interview will be shorter. However, some participants, although feeling uncomfortable or distressed, may feel obliged to continue as they do not want to let the researcher down. To combat this, the researcher will make it very clear that they are under no obligation to continue with the interview if they feel this way and the researcher will watch for any signs of discomfort or distress. The researcher will pause the interview herself if she thinks it is becoming too hard for the participant.

Another ethical issue is the potential imbalance of power between the researcher and the participant (Kelly, 2013). Whilst the researcher of this study is neither an expert in the field nor someone with high standing, sometimes this is the perspective of the participant and there can be an unintentional imbalance of power. In order to combat this, the researcher will allow the participant to choose where the interview will take place. Having the interview where the participant feels most comfortable will hopefully take away the power and meaning that might be associated with holding interviews in an office or clinic setting (Kelly, 2013).

Principles of ethical conduct

Tolich & Davidson (1998) describe five principles as a guide for conducting ethical research. The five principles include: to do no harm, to have voluntary participation, to have informed consent, to avoid deceit, to keep the identity of participants anonymous and/or confidential. These five principles have been expanded on by Mutch (2005) who has described twelve principles for conducting ethical research. These twelve principles include: informed consent, voluntary participation, right to withdraw, permission, coercion, deception, confidentiality, anonymity, privacy, participant safety, researcher safety, and dissemination. Of the principles included by Tolich & Davidson (1998) and Mutch (2005) informed consent, voluntary participation and the right to withdraw, confidentiality, privacy and anonymity, power, participant safety, researcher safety, and dissemination need to be considered for this research project.

Informed consent will be gathered from all participants prior to the commencement of the interviews. Participants will be emailed information sheets which they will be encouraged to read through thoroughly. If they have any queries or questions about the research they will be encouraged to get in contact with the researcher to discuss them. All participants will have the opportunity to either sign the consent form and email it back prior to the time of the interview or bring the signed consent form with them to the interview.

Voluntary participation and the right to withdraw is a key point in both the information sheet and the consent form. Those who are recruited through the snowball method will volunteer their contact details in order to be contacted by the researcher to find out more information. At no point will there be any pressure to participate in the research.

Confidentiality, privacy and anonymity will be maintained throughout the study. All participants will have individual interviews therefore participants will not be aware who the other participants are. The only person who will know the identity of the participants and will see the data is the researcher. All documents containing confidential information such as consent forms and transcriptions will be held in a locked filing cabinet and on a password protected computer. Participants will also be given pseudonyms to protect their identity in the research report.

Researcher safety is also an ethical issue due to her own experience she has had with stillbirth. She is also at risk for emotional distress as some of the interviews may resonate with her and bring up some heavy emotions. However, the researcher has her own support network within

her family and friends, and her supervisors, and if any further help is needed she has contact details for professional support.

Dissemination is the last ethical issue to be addressed. Participants will be informed through the information sheet that the thesis will be available through the University of Canterbury Library and also that it may be disseminated throughout healthcare professionals.

Ethical Approval

Ethical approval was sought from the University of Canterbury Human Ethics Committee and was granted on 12 October 2015. The interviews took place in November and December 2015.

Method

Research Setting

For seven out of the eight participants the interview took place at their home; however for one of the participants the interview took place at a private space at their work. Five out of the eight interviews were conducted with only the participant and the researcher present, the other three interviews were still conducted one on one with the researcher and the participant, however, for two of the interviews children were present in the home and for the one other interview the participant also had a support person stay with them.

Interviews

Overview

All interviews were conducted one on one and face to face. One participant had a support person with them during the interview; however the support person remained silent for the length of the interview. Not only did a semi structured interview fit within a qualitative descriptive paradigm, it also allowed for in depth answers and reflections from the participants that gave rich and plentiful data. Due to the sensitive nature of the topic, a semi structured interview was the most efficient and most respectful way to complete this research. It allowed the researcher to gather all the information required for the study and allowed the participants the opportunity to tell their story and give as much information as they felt comfortable with.

Sample

The target population for this study are parents who have had a stillborn child in New Zealand and who are of either gender. It is important to include males in this research as the existing research from a male perspective of having a stillborn child is very limited. Due to the target population requiring particular experience and knowledge, the first three participants were selected purposefully through the researchers own personal networks to fill the requirements of the research. These participants had specific knowledge and experience that would reveal useful information for the study (Kelly, 2013). Once these three participants were selected a snowball technique was employed to recruit the remainder of the participants. The snowball method of recruitment occurs through word of mouth and, in the case of this research, the first three

participants recruited were encouraged to pass on information to other potential participants who then passed on information to more potential participants, thus creating a snowball effect (Atkinson & Flint, 2001). The characteristics of the sample are presented below. A pseudonym has been given to each participant to ensure their anonymity, privacy and confidentiality.

Table 2: Sample characteristics

Participant	Year of stillbirth	Time between stillbirth and interview	Ethnicity	Gender
Shaun	2002	13 years	New Zealand European	Male
Leah	2002	13 years	New Zealand European	Female
Hannah	2002	13 years	New Zealand European	Female
Isobel	2001	14 years	New Zealand European	Female
Sophia	2000	15 years	New Zealand European	Female
Jacob	2005 & 2008	10 & 7 years	Maori	Male
Michael	2014 & 2015	1 year & 5 months	New Zealand European	Male
Laura	2002	13 years	New Zealand European	Female

The sample goal was to have between six to ten participants and this was achieved with eight participants in the sample. As the data was gathered through semi-structured interviewing, there was extensive information which was be rich in detail, this allowed data saturation to be reached with a limited number of participants (Atkinson & Flint, 2001).

Participants who were eligible to take part in the research had at least one still born child since 1995. This criterion is in place due to changes in the New Zealand definition for a stillbirth in 1995. Since 1995 the definition for a stillbirth in New Zealand is a child who is born dead and weighs more than 400grams or a child who is born dead after 20 weeks of gestation (Bascand, 2010). A second criterion to participate in the research is that the stillbirth occurred in New Zealand as the aim of this study is to explore, understand and describe the experience of those parents who have a stillborn child in New Zealand.

Recruitment

Initially, the aim for recruiting participants was to make contact with specific organisations and support groups who aid parents of stillborn children. However after receiving no response to contact made with specific organisations, the recruitment method was altered to the snowball method. The first three participants were selected through the researchers own personal networks to begin the snowball process. Participants either made contact with the researcher themselves through email or passed their contact details on to the researcher through other participants. The researcher then contacted each participant individually by either phone or email depending on what contact information was given by the participant. These communications explained more about the research and why it was being conducted, participants were also informed that they would be emailed an information sheet and consent form. With the email containing the information sheet and consent form participants were offered the opportunity to query any parts of the research or ask any questions before signing the consent form and participating in the research. Participants were also informed that they

could pull out of the research at anytime up until the point of analysis. No participants withdrew from the study.

Data Collection

For this research the data was gathered through the means of semi-structured interviews which were guided by the main research question, 'what is the experience of parents who have stillborn children in New Zealand?' An advantage of semi-structured interviewing is the interviewer may prompt the participant to explain the situation further so the interviewer can gain a greater understanding of the situation. A second advantage of semi-structured interviewing is that it enables the researcher to get clarification on unclear answers (Milne & Oberle, 2005). During the interviews both clarification of answers and prompts were used; this also ensured the validity of the participants answers.

The three main questions that guided the interview were:

- 1) Can you tell me about the experience/the story of having your stillborn child?
- 2) What was support like from family and friends?
- 3) Can you tell me about the experience of loss around losing your child?

Prompt questions were used throughout the interview when extra information or depth was needed about a particular topic. However these prompt questions differed for each and every interview as each participant's story was different.

All interviews were recorded with the participant's permission, these recordings were transcribed by the researcher and all participants were informed that they could have access to that transcript at any point to alter, add statements, or to check that the transcription was a fair representation of the interview. Before using any parts of the interviews in the final report, the researcher contacted all participants to offer them the opportunity to read their transcript. None of the participants made any amendments to their transcript and they were happy for their interview to be included. The themes drawn from the interviews are presented in the next chapter.

Chapter 4 – The Experiences

Introduction

Thematic analysis was the method in which the data from the interviews was analysed. This comprised of initially reading and rereading the interviews to become immersed in the data. Once the researcher had a good feel for the data she began rereading the interviews again, this time highlighting common elements between the interview transcripts. The researcher performed this process twice to ensure she had not missed any commonalities. At this point the researcher went through each transcript and made a list of the common elements which she had highlighted between the transcripts and grouped together similar aspects which were the emerging themes. The researcher reread the transcripts again to ensure she had not missed anything important and came to the conclusion that the transcripts had been read through thoroughly and all the common elements had been identified.

Through thematic analysis the researcher identified common themes within the stories which allow us to understand what it is like for parents in New Zealand to have a stillborn baby. The data analysis revealed six themes; 'moving with the times,' 'the importance of staff,' 'the influence of society,' 'moving forward,' 'grief' and 'the father's perspective.' These themes along with sub themes will be discussed further below with comparison to previous literature. Excerpts of participants' transcripts will be used to further clarify and give evidence in support of the themes. Using the participants own words allows the participants to speak for themselves with no researcher bias.

Moving with the times

‘Moving with the times’ highlights the changes in care for parents of stillborn children. The New Zealand healthcare system has implemented practices and policies that adhere to current thinking, which is guided by all present research, about what is best practice for the care of parents who have stillborn children. The excerpts below verify the implementation of such practices and also show the benefits of them.

Creating memories

Prior to the 1970’s babies were taken away from the parents, denying them the opportunity to see, hold or bond with their baby. Healthcare has moved on from this practice and hospitals within New Zealand are following trend (Crawley, Lomax, & Ayers, 2013). Every participant in this research had the opportunity to meet, spend time, and create memories with their baby. Creating memories with their baby ranged from anything between holding and dressing their baby to taking photos, introducing it to family and friends and taking prints of its hands and feet.

‘I didn’t dress her my midwife did because she was really, really little (...) we saw her and held her, my mum came up and saw her (...) the midwife took her hand and foot prints so I’ve got those, in fact I’ve got the death notice cut out and feet laminated and in my wallet.’ (Isobel)

‘He was so tiny, he was just sitting in the palm of our hands (...) we have his wee feet and hands and a photo of him (...) my aunty and my granny came up to see us and they saw him (...)

then [oldest daughter] came in and I wasn't sure I wanted her to see him I didn't want to scar her but she fought hard to do it so I said I was happy for her to see him and she was stoked she got to see him.' (Hannah)

The opportunity for parents to spend this quality time with their child means that parents are able to move forward with their life without wonder or regret. Whilst all of the participants in this study met and held their baby, one of the fathers' wives chose not to see her baby, she did not think she could face her dead baby but from her husband's account of their experience, she struggled with her grief after not seeing and holding the baby.

'She is European and not used to things with death, mate as we call it, it took a long time for her to come to terms with that [the death of her baby] because there was guilt associated with not holding the baby and having that opportunity to grieve, that was difficult, very, very tough' (Jacob)

These accounts show that giving parents the opportunity to see, hold, and spend time with their baby is helpful for them to grieve and cope with the loss of their baby. Parents in this study were grateful to have those opportunities. These experiences support previous literature suggesting parents should see, hold, and create memories with their baby as it encourages healthy grieving and coping and will have a positive effect on their recovery from the stillbirth (Kingdon, Givens, et al., 2015; Kingdon, O'Donnell, et al., 2015; Ryninks et al., 2014). It is suggested by Kingdon, Givens, et al. (2015) and Ryninks et al. (2014) that parents who do not meet their baby can regret this decision at a later date. Also, parents who do meet and spend

time with their baby can also have regrets about not spending enough time with their baby. While all of the parents in this study met their baby, the wife of Jacob did not and he mentioned grieving and coping was very difficult for her. Seven out of eight participants also had as much time as they needed and wanted with their baby, Hannah did not. However, this was not her choice and while she cannot regret this as it was not her decision, she does wish that she had more time with her baby. These two cases support the notion that not meeting the baby or not getting as much time as needed can cause regrets or difficulties coping at a later date.

Funerals and taking baby home

Not only was it extremely common that parents met, spent time and created memories with their child but this research shows it is becoming more common for parents to have a funeral or some type of ceremony for their baby. Between the birth of the child and the funeral, parents also had the opportunity to take the baby home with them. Seven out of eight participants had the opportunity to take their baby home and hold a funeral. They have fond memories of the time they spent at home with their babies and the services that allowed them to share their baby with their family and friends.

'She lay in her basket for a few days, then we had a naming ceremony a wee funeral at home (...) lots of people came (...) I remember one girl came to visit with flowers but she wouldn't come in because she was too scared to look in the basket (...) she just looked like she was asleep she didn't look like a dead baby, she was actually bigger and heavier and longer

than [oldest daughter] (...) it made her real, for the kids too (...) she didn't have to come home but it wouldn't have been, she wouldn't have been a memory' (Leah)

'Our almost two year old was really involved and inquisitive (...) he kept wanting to wipe his nose because there was fluid coming out of it. My parents were overseas, so they came over and helped out and we had a funeral service for him which was nice and our church was really supportive of us (...) at the funeral there was a whole lot of monarch butterflies that kept circling around us and the pastor when he was doing his speech, I can't even remember the story now but it was some kind of analogy with a monarch butterfly so it was just really bizarre that these monarch butterflies were flying around and so now every time I see a monarch it reminds me of him.' (Laura)

Of the seven participants who had the opportunity to hold a ceremony for their child and take their child home, six held a ceremony for their baby and four took their baby home with them in between them leaving the hospital and the ceremony. One family would have taken the baby home had it not been extremely premature.

'I didn't bring her home because I had the kids, the other two were quite little and coz she didn't look, because she was born so early she was discoloured and I wasn't gonna bring her home, she was a bit scary for the kids (...) if she had been full term and looked like a sleeping baby then maybe I would've brought her home.' (Isobel)

Hannah had a particularly horrible experience with staff nearer to the end of her time in hospital.

'Afterwards we left, we could've stayed but the next shift came on after three and the lady came in and said why are you still here, you gave birth it was only 22 weeks, what are you still doing here, come on there are other people out here that need better attention than you. I just got up and walked out (...) If I could've taken him home I would have (...) I would've loved to have stayed and spent more time but we weren't allowed (...) although I do stand up for myself (...) I couldn't, I didn't and I normally would've said get stuffed I'm staying but I was so traumatised by it all' (Hannah)

Crawley and colleagues suggest that sharing memories of the baby with others can be just as beneficial to the parents as making memories with the baby. Firstly, they reason that sharing memories is an integral part of any grieving process. Secondly, they state that sharing memories of the baby may help parents to integrate their lost baby into their life story and resolve the ambiguity of becoming a parent but not having the physical presence of the child (Crawley et al., 2013). Although not all parents in this study took their baby home with them, six out of the eight participants had at least one family member other than their partner meet their stillborn baby. For two participants this was in private during their time in hospital and for the remainder of the participants it was between taking their baby home and holding the baby's service. All participants who had this opportunity were grateful for the time and experience they had with their baby. For those parents who did not take their baby home or did not have a service, all but one commented that had circumstances been different (if the baby

being full term or more developed, if their partner was more comfortable with having the dead baby around, or if they were given that option) they would have taken up those opportunities. Therefore, this study supports the notion that allowing parents the opportunity to take their baby home and to hold a service and share those experiences with their friends and family can be beneficial to the parents' ability to grieve and cope.

Seven out of the eight participants had the opportunity to connect with their baby in the way that they desired. These stories show that New Zealand health professionals are respectful of the need for parents to have the opportunity to spend time with their baby by holding, dressing, taking photos, and taking hand and foot prints in the hospital, and encourage parents to have time at home with their baby, family and friends. Although these practices do not dissipate the grief that parents carry, it ensures that parents have ample opportunity to fulfil their parental instincts within the short time frame they have with their baby.

The importance of staff

Staff are important to the care parents receive

Every participant in this research had different experiences whilst they were in hospital. This is firstly due to each stillbirth being unique; mothers have different pregnancy experiences and each situation unfolds in its own way. However, the impact of the experience for parents is determined by the healthcare staff: doctors, nurses and midwives. Participants mentioned the

importance that staff had on their care and that healthcare staff play a crucial role in the experience of stillbirth.

'We kinda felt like, ya know, ya got the impression that you weren't actually having your baby coz it's not 39 or 40 weeks, I don't know if anyone else had that impression, that was just, at the time the staff that was on, coz the staff have a lot to do with it, the night staff were coming off when I got in and the day staff were coming on and they were a lot nicer (...) I remember that two staff members were so much nicer than everyone else, when we gave birth they were there, one nurse was really good, she was lovely' (Hannah)

'They kept me in the labour ward for two or three days (...) they were fantastic, there were two or three nurses rotating, they couldn't have done enough for me they were amazing people but then I had to get moved out of there (...) I had to go up to the gyney ward coz that was the only place for me (...) that was the end of the lovely nurses (...) there was just no empathy whatsoever in that ward and I know that's not what they deal with in that ward (...) but there was just no understanding whatsoever, from where I'd come from, the ward below, where the nurse would sit and cry with you and couldn't do enough for you to these women, these nurses just being like robots pretty much and just not giving a shit, so in the end I left' (Sophia)

Both Hannah and Sophia were overwhelmed and traumatised by their stillbirth. They expected healthcare professionals to be skilled in caring for them. While they experienced some healthcare staff that were attentive to their needs, they also experienced healthcare

professionals that made the situation worse. Both Hannah and Sophia left the hospital due to perceived lack of care. For Hannah, that was the last time she saw her baby, if she had felt more comfortable and cared for by the healthcare professionals she would have spent more time with her baby.

These excerpts support previous research which suggests that the care that parents of stillborn children receive while they are in hospital is important as it can have a significant impact on the experience parents have and the feelings that parents associate with this time (Radestad et al., 2011; Saflund et al., 2004; Trulsson & Rådestad, 2004). A study from Trulsson & Rådestad (2004) showed that women can feel disrespected and deprioritised by healthcare staff when staff are not careful about their behaviour or style of communication; both of these feelings show through in the experiences of Hannah and Sophia. A study by Radestad and colleagues (2011) showed that women were grateful to healthcare staff when they treated the baby as if they were still alive, respected and supported their motherhood, and showed emotion. An example of this is shown in the excerpt from Sophia where she comments on the way one set of nurses were so engaged with her and her experience as the mother of a stillborn child that they would sit and cry with her.

Communication and information

Communication is crucial in any type of healthcare role and is especially important in relation to stillbirth. Firstly, a lack in communication can sometimes contribute to stillbirth, this occurred to one participant.

'It's still raw and more than anything now I get really angry about it because it could have all been prevented had they just listened to me and so that's a real hard one (...) that was the hardest thing for me for a long time, getting over the what ifs, what if I had just said this or what if they had just sent me for that scan. So that was the hardest thing and as I said it still makes me angry' (Sophia)

Communication is key for giving birth to a dead baby. The birthing can be daunting to any first time but with the added anxiety of birthing a dead child, clarity of supportive communication is paramount. For some mothers in this study they had experienced the process of being induced and giving birth before, however, some had not. Therefore, clear and succinct information about the details of how this will happen is very important for both the mother and the father.

'Once the scan revealed she was dead maybe there could have been better information about what the process would be and even after birth there was still no, kind of, someone coming in and saying this is normally the process that people go through post delivery ummm in terms of if ya wanna take the baby home or you don't wanna take the baby home , these are your options, these are your support services. There was none of that.' (Shaun)

Alongside the information that needs to be given before the birth, just as Shaun stated, after the birth more information needs to be given about the next steps to be taken such as registering the birth and death, the opportunity to spend time and create memories with their baby and what happens with the body.

'There was nothing, I had to ask what happens now? But nobody came and said to us, hey I'm sorry for your loss but this is the process now, this is what we have to do (...) what wrap around services were there? What support services were there? From a clinical perspective around sudden unexplained deaths in infants, well back then, none' (Jacob)

'My midwife gave me all the stuff, gave me a whole lot of papers to read when I got up there, you can have a funeral but you don't have to have one, how you have to register the baby's birth and death and all those sorts of things (...) so I did get all that information, and amazingly, I took it all in.' (Isobel)

Information about support services also needs to be given. Parents of stillborn children face turbulent relationships and agonising grief and help needs to be easily accessible to them. Three participants in this study received information about support services and five did not. Shaun found a particular gap in this area.

'Nobody was there to tell us how to deal with it, I don't recall anybody from the hospital or anything kind of directing us guiding us to any sort of agency or something which would help us work through that post birth period which, to me looking back it's terrible. Nobody was there to guide us or say hey these are some of the challenges you will face and these are some of the agencies that can help you or ummm these are the key take outs you need to realise to make sure things don't fall over (...) It's the long term effects that you want to avoid, so the lack of resources or knowledge given out to families post birth, for me, is a real gap. Whether the gap is still there today, I dunno, but certainly for us it was pretty much nothing.' (Shaun)

For the participants who did receive this information it was given to them in multiple forms, verbally from healthcare staff and visually through pamphlets. The participants who believed they received good information and resources had their lead maternity carer coordinating their time in hospital, this 'one on one' care provided parents not only with better information but better overall care.

Previous studies show similar results that the quality of information and communication provided by healthcare professionals has a significant impact on the experience of stillbirth (Lisy et al., 2016; Malm et al., 2011; Radestad et al., 2011; Saflund et al., 2004; Trulsson & Rådestad, 2004). Lisy and colleagues (2016) synthesised findings from 20 studies to produce one major theme for each stage of stillbirth: diagnosis, induction and birth, immediately post birth, and post birth onwards. Induction and labour is the stage at which most information is given to parents and Lisy and colleagues (2016) concluded with this finding, 'sensitivity, the importance of preparing parents for the birth through clear and comprehensive explanation, preferences about timing of the birth and time to process information impact upon parents' experiences at the time of induction and birth of their stillborn baby' (Lisy et al., 2016, p.14) This means giving clear information that is understandable for parents, medical terminology or blunt language can leave parents feeling confused and that healthcare professionals lack empathy towards the parent's situation. Also, healthcare professionals must consider the parents emotional state; their ability to understand and evaluate the information given to them. Although parents are vulnerable during this time, all information and options must be given to the parents so they

can decide and prepare for induction and delivery (Lisy et al., 2016). In this research Shaun believed the information he received about induction and birth was lacking while others were well prepared for what was to come. Post birth and onwards is the last stage at which parents receive information. Lisy and colleagues (2016) concluded that 'health care professionals should be aware that the need for support may continue into the postpartum period and beyond, and may impact on care needs for any subsequent pregnancies' (Lisy et al., 2016, p.15) This means information for potential future support needs to be given at this time. This may include information on how to get in touch with psychosocial supports from psychologists, social workers, counsellors; information on some of the difficulties they may face with their partner, their children, their community, or their own mental health; or it may be information regarding practical things such as registering the birth and death or arranging a funeral (Lisy et al., 2016). While this information is less technical and may seem less important to the information received prior to induction and birth, both previous literature and this research shows us that parents are grateful to have this knowledge and when it has not been given to parents they have wanted it. Both Shaun and Jacob commented on the lack of this kind of support and the need for it to avoid any negative long term effects.

Lead Maternity Carers (LMC)

LMC's are either a community or hospital based midwife, a General Practitioner, a private obstetrician, or hospital maternity service that is chosen by the parents and coordinates their maternity care for the duration of their pregnancy, labour, birth, and postnatal care. In New Zealand all parents are required to have an LMC. In this research if a participant had their

preferred maternity carer coordinating their time in hospital this person will be referred to as an LMC. However, for a range of reasons, not all participants were able to have their LMC with them at the time of their stillbirth and they were cared for by the hospital staff that were rostered on at the time. These staff will be referred to as 'healthcare professionals.'

Clarification of these differing roles is important as the care provided by LMC's and healthcare professionals were perceived differently.

From the participants in this research, those who had their LMC coordinating their care in hospital were much happier with the care they received; they often were only cared for by their LMC. Parents who had LMC's managing their hospital stay appreciated that their care was private and seemed more personal just having one healthcare professional caring for them. They appreciated the open communication and the wealth of information they were given as it prepared them for what was to come next.

'I had a fantastic midwife (...) I didn't really see much of the other staff there coz I didn't really need to coz I had my midwife looking after me (...) in fact I don't think I had anything to do with them.' (Isobel)

'We really didn't see anyone else apart from our midwife, she met us there and she took us into a room that was meant for that kind of thing and so we just stayed in that room and we didn't have a lot of other people coming in and out, it was just her really ... she told us what to expect, what the baby would look like, I think I even remember her bringing in a doll to show us the size he might be and said what might happen and that sort of thing (...) I think my midwife

was pretty good (...) I don't actually remember seeing anyone from the hospital come in at all, it was all through her and that was quite nice, you didn't have lots of people coming in and out and it felt quite personal and that was good.' (Laura)

The care of pregnant women can differ across countries. Within New Zealand the LMC is most commonly a midwife whereas a General Practitioner or an Obstetrician is common in other Western countries. Maternity care is most commonly publicly funded with no cost to the parents in New Zealand, however, in other Western countries maternity care is sometimes privately funded by parents or their medical insurance or publicly funded but there is still some cost for prenatal and postnatal care. Prenatal and postnatal care is often community based in New Zealand, however, in other Western countries this care can be mainly hospital based. Most births within New Zealand occur in the hospital, this is also common across other Western countries, however, home births and birthing centres can be more common elsewhere (Rowland, McLeod, & Froese-Burns, 2012). The differences in who primarily cares for mothers during their pregnancy and what that care entails can provide challenges for comparing the LMC role and how they care for their patients. However, literature shows us that, whoever may be caring for the parents, parents prefer and are grateful for certain types behaviours, guidance, and care (Cacciatore & Bushfield, 2008; Erlandsson, Säflund, et al., 2011; Kavanaugh & Moro, 2006; Lisy et al., 2016; Pullen et al., 2012; Radestad et al., 2011; Säflund et al., 2004; Schott & Henley, 2010).

Parents were grateful to healthcare professionals who genuinely cared for them, not because it was their job but because they felt empathy towards the situation they were going through (Downe et al., 2013; Radestad et al., 2011). When healthcare professionals authentically cared for the parents' they were more likely to be sensitive to the timing and understanding where and when certain conversations, behaviours or gestures, and relaying of information was appropriate (Downe et al., 2013; Lisy et al., 2016). Throughout the literature many parents have remembered and commented on careless and insensitive comments or actions from healthcare professionals (Gold, 2007; Trulsson & Rådestad, 2004). Parents' were also grateful for the ability to make their own decisions throughout this process such as the timing of induction and options about post birth opportunities with the baby (Downe et al., 2013; Lisy et al., 2016). Although parents' could make their own decisions they were grateful to healthcare professionals who gave them information and guidance to make fully informed decisions, this included information about the process of induction and birth, preparing for the baby's arrival, and encouragement to see and hold the baby, to savour memories, and collect mementoes (Downe et al., 2013; Kavanaugh & Moro, 2006; Lisy et al., 2016; Radestad et al., 2011; Trulsson & Rådestad, 2004). Parents were extremely frustrated when this information was inaccurate or insufficient and caused them distress (Downe et al., 2013; Trulsson & Rådestad, 2004). Parents were grateful to healthcare staff that treated their baby with care and respect and that respected them as the parents to their new baby (Gold, 2007; Kavanaugh & Moro, 2006; Lisy et al., 2016; Radestad et al., 2011). Parents also preferred continuity of care as it made them feel secure and that the staff were dependable (Downe et al., 2013; Lisy et al., 2016; Trulsson & Rådestad, 2004). Information and education for post birth and onwards was also something

that parents were grateful for and often helped them to understand their own grief (Gold, 2007; Kavanaugh & Moro, 2006; Lisy et al., 2016).

In this research parents who had their LMC coordinating their time in hospital received the majority of the caring qualities above. Other parents received some but not all of the care suggested above and they noticed specific qualities of care that they thought were missing or needed improvement. Whilst having their LMC present was not an option for all parents in this study the care given by LMC's should be given by all healthcare professionals who work with parents of stillborn children. All parents should receive care that feels personal, private, empathetic, respectful, and informative.

Support and care from healthcare professionals

Although some participants believed that more could be done in terms of giving more information and resources to parents during their time in hospital, the majority of participants experienced healthcare professionals who were supportive and caring and empathic to the situation they were going through. The following accounts show times when participants had healthcare staff that provided this type of care.

'I think 99 percent of people who work in those situations and units are always very supportive anyway, it's a part of their makeup and that's why they do those jobs, certainly the people personally were lovely and caring and genuinely concerned for your well being' (Shaun)

'I was really impressed by the majority of the midwives, hospital midwives who took care of us, we actually asked them about it because it has to be a horrible job to do and they said only the midwives who want to be working with parents in our situation actually do that, so we were immensely grateful to the midwives who looked after us, they were very kind.' (Michael)

The above examples show the importance of staff throughout the stillbirth process and show just how influential they can be. Although not mentioned in this excerpt, Shaun felt like more could have been done in terms of information and after care support, however, he was grateful for the emotional support he received and was thankful that those healthcare professionals were there to support him and his partner in their time of crisis. Michael and his wife were also grateful for the emotional support they received in their time of need and were thankful for those healthcare professionals who do this tough job.

Literature suggests that emotional support given to parents during their time in hospital can be varying. As with this research, while some parents were happy and even impressed with the emotional support they received from healthcare staff, some were disappointed. From the literature those who are disappointed with the emotional support they received most commonly make comments around feeling neglected or avoided by staff, that staff made insensitive comments or actions that minimised the parents' grief, or treated the baby disrespectfully (Gold, 2007). Parents who were happy with the emotional support they received often commented that healthcare staff would go beyond their regular duties for them. This included: visiting more regularly and spending more time with the parents; talking about the

baby with the parents and caring for the baby as it were still alive; and allowing the parents to grieve and sometimes grieving alongside them (Gold, 2007; Radestad et al., 2011; Trulsson & Rådestad, 2004). The way in which healthcare staff communicated with parents could also be classed as more or less caring and supportive by the way the information was expressed and the type of language that was used (Saflund et al., 2004). Small gestures and considerations seemed to make a big difference in the quality of emotional support received.

The Influence of Society

Difficulties with family and friends

In the literature read prior to and alongside this research, social awkwardness and ambiguities of how to approach stillbirth were common (Crawley & Jones-Brierley, 2013; de Montigny et al., 1999). Parents often found little support from family and friends; and if they did, it didn't last for long as often they didn't understand the complexity of the grief that the parents were dealing with (Crawley & Jones-Brierley, 2013). However, many of the family and friends of parents of stillborn children avoided the parents as to avoid the discomfort of talking about the dead baby (Crawley & Jones-Brierley, 2013). However, none of these studies occurred in New Zealand and therefore this study is crucial in gathering information so we can begin to see what the social experience is like for the parents of stillborn children in New Zealand.

Of the eight participants in the current study four mentioned some sort of awkwardness or discomfort between them and friends or family members.

'Those things can always be a bit awkward for family and friends because ya just don't know what to say to somebody who has lost someone, especially a child, so that becomes a bit of an added pressure because quite often you feel obliged to make the other people feel comfortable ya no, so you get pressure from all different angles and it might not be real pressure but its pressure that's real at the time in ya head ya no' (Shaun)

'I think it's inevitable that people feel awkward and don't know what to say and that's true with friends as well as both my dad and sister told me they looked online to see how to help people in this situation, thank God they are both savvy enough not to follow the advice they found blindly (...) what is tricky and infuriating about being in our position is that people do understandably feel awkward but when people try to react to it in ways that, in my mind, are more about getting rid of that discomfort than they are about actually what is happening for us, it is like people are saying platitudes for their own benefit so they think they are at least doing something but I would rather they just feel awkward and say nothing.' (Michael)

These platitudes that Michael spoke about, other participants also brought up. Participants found them unhelpful and hurtful.

'I got these cards, one was from a religious lady and she said well at least it wasn't full term, and it's funny, my sister in law, she gave birth and her baby died and she gave birth to a full term and she said that to me too, I don't know what you're crying about it's not like it was full term (...) I would just never dream of saying that to somebody even if they miscarried'
(Hannah)

For one participant a particular situation was awkward when her sister had a one month old baby. Parents in this situation or a similar situation may feel just as uncomfortable seeing newborn babies with friends and family or even strangers.

'It was awkward with my sister because she had a baby who was one month old, so we were pregnant together and she had her daughter and obviously I had mine.' (Leah)

'It's just that terrible loss, and then seeing pregnant women and other people with babies it was terrible and I remember lying in bed thinking I just don't wanna get out, I just don't wanna get up, just don't wanna, but I had to' (Isobel)

The awkwardness and discomfort felt by family, friends and the community of parents of stillborn children has been documented in previous studies. Crawley & Jones-Brierley (2013) have suggested that the support or lack of it can lead to the spoiling of identity for the parents of a stillborn baby. They document experiences of the participants from their study which are similar to the experiences illustrated above from parents of this study. Often friends, family and acquaintances struggle to know the right words to say to the parents or they decide to not say anything at all. Parents from the Crawley & Jones Brierley (2013) study describe feeling like a leper due to being avoided by some of their friends and family. When family and friends did converse with the parents about their stillborn baby, comments that were intended to be positive were often perceived as insulting by the parents. The platitudes that Michael spoke of and the comments that Hannah shared are similar to comments that were shared in a study by

Cacciatore (2010). Participants shared examples of platitudes such as 'you're young, you can have more,' 'at least it wasn't one of your older children who died,' or 'at least you didn't have to bring the baby home and then have it die' (Cacciatore, 2010, p.144). Whilst people are trying to provide positivity about the situation, it often leaves parents feeling lonely and misunderstood. Women also felt awkward being around other pregnant women and babies. Crawley & Jones-Brierley (2013) also found that mothers of stillborn babies would avoid taking subsequent children to toddler groups or other similar events to avoid awkwardness in conversation between themselves and other parents. Often questions such as 'is this your first child?' can be awkward as the honest answer can cause discomfort for other parents. Sometimes women would lie and say it was their first child to avoid that discomfort but often made themselves upset that they had to lie and pretend their stillborn baby did not exist.

While half of the participants in this study did encounter some awkwardness and discomfort from friends, family, and other acquaintances, it was not a common occurrence. This leads to the next sub theme that parents of this study had good support from their friends, family and community.

Good support overall

Although for half of the sample awkwardness and discomfort was mentioned in their experience it by no means was a regular occurrence and did not overshadow the good support that they did receive from family and friends. For the other half of the sample no awkwardness or discomfort was mentioned at all and they all experienced good support from both family and

friends. Some of the best experiences of support from family and friends were those who encouraged light heartedness whilst still being sensitive to the grieving parents.

'I remember one lady at the afternoon tea after the funeral, she was really vivacious and outgoing and she kept everything really light and she wasn't joking about this experience but it was just really nice, it meant it wasn't just a sombre event where nobody knows what to say because you do want to celebrate his life as well as grieve and I remember just appreciating her being and keeping it upbeat and sensitive as well' (Laura)

'We had really good friends and we are reasonably laid back people that are easy to get on with and that meant the support we did have was good support and people, at times, were ok about still having a laugh and making light of different situations.' (Shaun)

Other participants who had good support mentioned that this support came from people who had been through the same or similar circumstances of losing a child. For some people these support people were friends and family members and for others it was support groups in addition to their friends and family.

'I think you will come to understand, like we have, when something like this happens it's those closest to you that it's happened to as well, they have lost children first, second trimester, it's more common than you think. It's not till something like this happens that they open up and tell you, it's like the old dirty little secret that nobody talks about, the loss of their children, for a myriad of reasons I guess.' (Jacob)

'It was amazing actually, with the support from our church, there were a lot of women that I didn't know that had had their own journeys, some had had stillborn babies and the pastor's wife had had a full term baby the year before so she understood stuff and you just heard a lot more of people who had miscarriages because people don't tend to talk about it too much, so definitely felt support' (Laura)

'We got contacted by SANDS the neonatal support group, so I was involved with them for quite a few years and they were really good, I found that really helpful to begin with, a whole lot of women in the same position as you, I mean people try to understand and be sympathetic and supportive to you but people think you didn't even know your child but it's not just that, you're saying goodbye to your hopes and your dreams and how you saw your life to be and a lot of people don't really get that so the support group is great (...) they were wonderful and even in my pregnancy with my daughter they were wonderful they would ring and see how I was with my pregnancy and after she was born, she was born really prem, they were rocking up with dinners, what can we do for you (...) we had become friends for the worst reason.' (Sophia)

The Cacciatore (2010) study identified the common theme throughout the study was comments from parents that social support was one of the key things that helped get them through the stillbirth. Parents mentioned that validation of grief from others was important to them. Sometimes this validation came from friends and family members but like the current study, validation often came from other grieving parents. While validation of grief is one way to support parents of stillborn children, Kavanaugh and colleagues suggest that there are many

other ways as well including, emotional support, advice and guidance, financial and material support, practical assistance, and socialising. Emotional support and advice and guidance align with validation of grief as they comprise listening, encouraging, accepting, and sympathising with the parent's feelings. Support in other forms was also seen as helpful from parents. Financial or material support such as cards and flowers were seen as nice gestures and showed that others were thinking of them and their loss. Practical assistance such as childcare or preparation of meals provided comfort to parents as others were caring for them. Socialising may seem an odd form of support but friends who popped over for coffee often provided a distraction and lightened the mood (Kavanaugh, Trier, & Korzec, 2004). Parents from this study, while they may not be mentioned above, also described some of these other forms of support discussed by Kavanaugh and colleagues.

Difficulty socialising

Whilst some participants found the support of friends and family members helpful in moving forward after the stillbirth some participants found it particularly difficult to socialise during this time. Michael explains his feelings about this time which shows that the drive to move on and the will to grieve can often be confusing and can sometimes not coexist.

'It has felt really hard with friends because they have been really supportive but at the same time it has been quite awkward and they don't know what to do and I feel quite torn too, part of me wants people to acknowledge it and talk about it because it's important but a part of me wants to enjoy things as they were before and hang on to those parts of my life that were

enjoyable. It has been really quite hard so I have tended to talk to some about it and not with others and just leave it in the background and carry on.' (Michael)

'But it was after that I reckon was the hardest, I'm a very outgoing person, real vocal, I don't usually keep everything inside (...) but with him, I didn't retreat inside myself but I had some really good friends but I just couldn't, just didn't want anyone's company, I just wanted my family's company, I just wanted my husband and my mum (...) I just wasn't ready to intermingle and talk about it and then I had to go, I had two weeks off work and then I went back to work and I was a wee bit more prepared but I still couldn't socialise, I couldn't bring myself to socialise yet.' (Hannah)

Support from friends and family and friends is regarded as a good thing for parents of stillborn children, however, if parents are not ready to socialise with friends they should not be rushed, as doing so may cause more harm than good. However, it is important to note that parents who exclude themselves or are excluded by others for an extended period of time can have a permanent effect on their social networks and their overall wellbeing and happiness (de Montigny et al., 1999). Maintaining closeness with family and friends throughout this period can be especially nourishing and can reduce the risk of anxiety and depression and increase wellbeing and happiness (Cacciatore et al., 2009; de Montigny et al., 1999).

Differences between partners

As shown in the excerpts above moving on and getting on with life outside of your immediate family can be hard but a few participants in this study also had trouble with their closest family, their husband or wife or partner. For some couples experiencing the stillbirth together and having that shared experience brought them closer together, whereas for others, the challenge of moving through the grief and understanding what the stillbirth meant for the future of their relationship was often what led to the relationship's demise. Of the eight participants interviewed for this study, five out of eight are no longer with the partner they were with at the time of the stillbirth. Participants in this study did not say that the stillbirth of their child was the cause of the relationship's demise but some participants did mention that it did add to stressors that potentially already existed. The following excerpts illustrate some of the strain that the stillbirth put on the parent's relationships.

'I guess because it was a child that we shared, by default, ya felt like ya didn't have ya partner to go to (...) the person that was my main crutch and possibly the same for her although she would have been going through a whole lot of other feelings as well, having carried her and delivering her, so I'm not sure what her reasons were that she couldn't talk to me but ummm mine were more about not burdening her, she just lost a child, last thing she wants to do is be dealing with my feelings. That's how I viewed it (...) I didn't have the person I normally would have had to lean on and that left me very few other people to be able to do that with' (Shaun)

'I had a husband who wasn't dealing with it, wasn't dealing with anything, it wasn't his thing and we never ever talked about it which became a barrier for us in the end among other things, so that was never ever resolved so there was that difficulty. As well he was saying he didn't want any more children and I did so that was pretty ugly there for a while' (Isobel)

'For her being told (...) that if she was to get pregnant again she would be putting her own life at risk and I think that was a part of our demise, we split up because she wanted to have more children and I was opposed to it and I understand why she wanted too (...) but the reality is if we did she probably would have died as well' (Jacob)

The next excerpts are from participants whose relationships did survive the stillbirth however participants said it was not easy.

'Well we had no choice, we weren't offered anything, you know it either makes you or breaks you so I dunno why but we did it, and you know I ate and ate and he fed me (...) but yeah we got through it (...) I didn't know what to do, where to go, I didn't know anything' (Hannah)

'My normal response is to become more rational and detached and my wife will do that sometimes but she also gets upset and she'll work herself up and when she starts to feel it she makes it worse and worse for herself and sometimes I find that difficult to cope with but I comfort her as best I can but it's just her process. I think the biggest challenge is if we both have a shitty day and I'm sad and angry and she feels the same but it feels better to feel that way together and grieve and cry together and just be doing that together (...) I think there are

always times where its created a bit of distance but I think we have navigated it quite well. I think we are both mindful enough that when I'm upset and [wife] is really overwhelmed, I can say I feel upset and shitty but she is a lot more vulnerable than I am so I can put that aside and come back to it and she does the same for me' (Michael)

Differences between partners can also occur cross culturally. In this study I had three couples who were in a cross-cultural relationship and of these three couples two said that they had differences of opinion when it came to decisions about seeing the baby, bringing the baby home, and having a funeral. These decisions were made at a time when both parents were trying to grieve and cope together and the decisions were made for the right reasons at that time, however, two of the three participants in cross-cultural relationships said that they would have done things differently if they could have.

'We took her home and this was the night before the funeral and with my ex husband, he was a Maori so it was quite a big deal, I didn't like it very much, I wasn't feeling very well, I just wanted quietness, I just wanted my own little family around me but they did their thing but there was quite a few people there that night and we had the service the next day (...) they wanted this big thing and I really didn't want that, if it was up to me I would have had a small service and that's it' (Sophia)

'We didn't do the normal Maori thing of bringing her home for three days because she was so small and they deteriorate quickly (...) Normally where I come from they wouldn't leave baby at the hospital but I didn't have any family around and [wife] needed me more because

she was traumatised (...) the difficulty with me being Maori and her being Pakeha, they are uncomfortable with death and [wife] didn't want her to come home, it's just a difference in culture, I wouldn't think twice (...) I left those decisions to what [wife] wanted because she was just so traumatised, brutalised, traumatised, wasn't functioning so just working with her to see what she wanted' (Jacob)

The third cross-cultural couple were happy with the choices that they made together; they both wanted to include their culture in the sending off of their baby and believe that the experience brought them closer together.

'We have the Samoan side of our culture and that was something we wanted to keep a part of and have a funeral and everything and we had him home a few nights before we went ahead with the funeral (...) I think it actually brought us closer together, just having that shared experience. I guess because he had never met the baby before, only felt it through me and didn't carry him and never saw him alive it was slightly different for [husband] than it was for me, still really upsetting and horrible for him but it brought us closer together than apart' (Laura)

The excerpts above from this study show that their relationships can be turbulent and while some relationships can endure through the challenges stillbirth creates, many do not survive the challenges of stillbirth. Previous research supports the finding that marital or equivalent relationships can be turbulent after a stillbirth, suggesting that this is due to the individual nature of grieving and coping and different expectations and expressions of grief and coping that each parent goes through (Avelin et al., 2013; Mcgreal et al., 1997; Samuelsson et al.,

2001; Wallerstedt & Higgins, 1996). Research suggests that fathers move through mourning phases faster than mothers and are more silent in their grief, whereas, mothers were slower to move through mourning phases and needed to talk about their experiences and feelings (McGreal et al., 1997; Samuelsson et al., 2001). These differences can increase vulnerability and misunderstandings and create barriers in the partnership. Further research found that parents who accepted differences and mutually respected each other's grieving and coping process reported more strength and cohesion as a couple (Cacciatore, DeFrain, Jones, & Jones, 2008; Samuelsson et al., 2001; Schott & Henley, 2010).

Moving forward

Becoming parents again

Although being the parent of a stillborn child is one of the most shocking and traumatising things that might happen to a person, many of the participants in the study have shown resilience to move forward with their lives and face the challenges that come with having a stillborn child. Many of these parents have become parents again despite the setbacks they have faced. Of the eight participants in this study five have gone on to have more children.

'I remember lying in bed thinking I don't wanna get out, I just don't wanna get up, just don't wanna but I had to and then life and time is a great healer and he [her youngest son] was the best healer, he was born two years later, just about two years later so that was the biggest healer really another baby' (Isobel)

Although for many parents it was healing to have another child, it was not without its challenges. Many had to overcome guilt and blame that they put upon themselves and premonitions about the future of their next baby.

'I remember always thinking I used to like having baths when I was pregnant and a couple of weeks before he died I had a really hot bath and imagine if it was too hot for him and it was that that killed him but I had to work through that and my midwife reassured me and yeah so I guess I was a wee bit more careful about what I did during this pregnancy (...) and when we got to the end it was like phew we made it.' (Laura)

'I was a bit stressed, terrified that the same thing was going to happen. Then my mother, towards the end of the pregnancy bought clothes but I wouldn't let her give them to me so she had to keep them at her place and when she finally gave them to me a couple of weeks before he was born I kept the labels on them, in fact I think they went to the hospital with the label on just in case I had to take them back, my midwife was laughing like what is this. I was terrified, I couldn't relax until he was safe, the further I got on with the pregnancy I would tell myself surely, surely he has to be a boy because he has got further along than the girls and surely he's gonna be alright but I just never knew so it was a bit of a stressful pregnancy.' (Isobel)

'I felt like she was going to die, in my mind as a coping mechanism, that the same thing was probably going to happen again and I didn't tell anyone till I was four/five months pregnant and I had her at six months so she was born three months early so I just didn't prepare anything, I didn't have anything ready for her, I just thought I'll prepare myself for the worst and if it

didn't happen that was a bonus and if it does, no surprises. So I was pretty sure all the way through, I was very ho hum about it, I wasn't excited about it (...) and being born premature I thought she is definitely going to die now and I remember the day they told me she could go home tomorrow, I was like oh shit! I had to race home, I had nothing, hadn't thought about it, I hadn't unpacked anything or made up a basinet, it hadn't crossed my mind, I think the baby room was full of junk at the time and I had nothing organised coz I thought what's the point she's not going to come home' (Sophia)

Once becoming pregnant again parents took nothing for granted, they were all too aware that pregnancy and giving birth does not always end in happiness. Whilst being pregnant and going through that experience was not a particularly easy time, parents were grateful that their baby was born with no complications. Whilst this study did not measure psychological morbidity and none of the participants mentioned any significant mental health issues, previous research has documented the psychological difficulties parents of stillborn children face during a subsequent pregnancy. Literature shows it is common for both mothers and fathers to feel uneasy and anxious going through a subsequent pregnancy. While levels of psychological symptoms differ for every parent based on their own individual circumstances it is common to be fearful and anxious that their pregnancy will have the same agonising outcome as before (Hughes, Turton, & Evans, 1999; O'Leary & Warland, 2013; Surkan, Radestad, Cnattingius, Steineck, & Dickman, 2008; Turton, Hughes, Evans, & Fainman, 2001; Turton et al., 2011; Turton, Evans, & Hughes, 2009). Previous studies have found mothers of stillborn children are more likely to experience depression, anxiety, and Post Traumatic Stress Disorder in their subsequent pregnancy. These

conditions are more likely to be experienced if the subsequent pregnancy is conceived within a year of the stillbirth (Hughes et al., 1999; Turton et al., 2001). In a study looking at psychological symptoms of fathers of stillborn children during a subsequent pregnancy, it was found that fathers also experience significant levels of anxiety and Post Traumatic Stress Disorder, however, at all points during the study the fathers symptoms were less than the mothers (Turton et al., 2011). For the majority of parents this vulnerability to psychological morbidity was transient as levels of depression and anxiety were significantly lower after a successful subsequent pregnancy (Cacciatore, Rådestad, & Frøen, 2008; Hughes & Riches, 2003; Turton et al., 2011). Due to the psychological morbidity parents of stillborn children are vulnerable to experiencing during a subsequent pregnancy it has been suggested that parents of stillborn children have access to increased support and supervision during their next pregnancy (Cacciatore et al., 2008; Lisy et al., 2016; Turton et al., 2009).

Including the stillborn baby

Although many of the parents will never finish grieving for their lost child they have learned to live with it and the inclusion of their lost child in their life has helped them to do this.

'I'm not sure that I've dealt with it completely or in the right way (...) although ya manage it better, I'm not sure we have finished grieving, like some days I miss [stillborn daughter] so much, like it's funny that you can miss something you never really had' (Shaun)

'Just as I was getting outta the car one of the songs that we played at her funeral came on and I said oh it's her song um and her ashes are buried down at the church where I got married and where I went as a child on [name of road] there so we go down and take flowers often and put a memoriam notice in the paper on her birthday and yeah we talk about her a lot, in fact I've got a tattoo on my, I'll show ya if ya like, of her feet and [oldest son], my oldest boy who's in the army, has the same feet and the [surname] family motto on the inside of his arm, so she is a big part of our life and [youngest son] wasn't born but we still talk about her all the time.' (Isobel)

'My mum made me, for Christmas, a scrabble board and his name is up there (...) the girls and [husband] got me this necklace and his name is on here so he's acknowledged within our family' (Hannah)

'[son] doesn't remember the actual time but he still, we have five children altogether now not including [stillborn son], and he is the eldest and then after [stillborn son] we had a daughter who is 12 now so [stillborn son] would have been 13 and he still often says he wishes, and he doesn't wish that he didn't have a sister, but he wishes he had his brother to hang out with and he is really into rugby and stuff and often he says if [stillborn son] was here we could do this and this together. So it has affected him and we do talk about it sometimes with the kids'
(Laura)

Unlike the previous era, stillborn children are regarded as an important part of their parent's lives and something that they continue to share with their family. Bremborg & Radestad (2013) and Murphy & Thomas (2013) suggest that it is the new era of care in healthcare where it is now advised that parents see, hold, and make memories with their baby that has given rise to the continuation of the connection and bond that parents feel with their stillborn baby. Material objects are seen as very important in memorialisation and the ability for parents to collect memorabilia of their child helps them to stay connected to their child years after the child was born. Items such as pictures and possessions of the baby help the parents to construct an identity for the baby and reinforce the place of the child within the family. When these items are on display in the home, it allows the friends and extended family to understand that the stillborn child still has a place in the hearts of the parents and in the heart of the family structure. Out of eight participants in this study, five regularly included their stillborn child in their lives, whether that was talking about them, visiting their grave, or having pictures or memories of them in their home. The stillborn baby continued to be a member of the family and was talked about by all family members, even siblings who weren't born at the time of the stillbirth.

Continual grief

Even today, for some parents it has been over 10 years since the birth of their stillborn child, they have not finished grieving, they are not sure they ever will. Whilst they have learned to manage their grief, it is still a part of their lives today.

'But it has been 13 years now and we are busy with lots of kids now and I don't feel like it is something that has held me back or that I am still in absolute grief over, I feel like it's a process and at times I might have a wee cry and we visit his grave on his birthday and we often talk and say imagine if [stillborn son] was here but it's more we have that promise that we will see him again in Heaven when we die so it's alright.' (Laura)

'I'd go for a drive and cry in my car and I still, not as often, but still do now if I have days where I think of [stillborn daughter] and I'll just be in my car and yeah get a bit upset so I'm not sure that I've dealt with it completely (...) although ya manage it better, I'm not sure we have finished grieving, some days I just miss [stillborn daughter] so much, like it's funny that you can miss something that you never really had' (Shaun)

Whilst having a stillborn child was upsetting and traumatising, all of the parents in this study were able to overcome the challenges they faced in the aftermath of the stillbirth. Samuelsson and colleagues found in their study that while parents had learned to cope with their loss the grief for that loss was always going to be there. One of their participants articulated this phenomenon well 'You can't affect what has already happened; you just have to go forward. But of course you have to deal with the extra baggage you are carrying and stow it in the right place and take it out at times when necessary. And you have to pack it right in order to travel on. Otherwise, you'll come to a halt, and then of course you need help.' (Samuelsson et al., 2001, p.128).

Grief

Multifaceted

All parents in this study, both mothers and fathers, grieved for their baby, whilst some grieved for the baby they had come to know and love over the gestation period others grieved for the loss of the life they had planned with their baby. Whilst parents grieved differently and grieved for different reasons, grief occurred across 100 percent of the sample and was deemed to be a regular response to having a stillborn baby. Not only did parents grieve for the child they had lost but so did siblings and grandparents to the stillborn baby.

'[daughter] came in and I wasn't sure I wanted her to see him I didn't want to scar her but she fought to do it so I said I was happy for her to see him and she was stoked she got to see him (...) When my stepdad came back from Australia I was brave for him because he was just beside himself with grief and my mum (...) she was beside herself with guilt and grief, guilt that she couldn't have been there and grief' (Hannah)

Whilst earlier thinking was that parents of stillborn children shouldn't grieve for their stillborn child because they did not know their child, the opinion of today is that parents do, in fact, get to know their child over the gestation period vicariously through the mother's stomach and through regular and three dimensional ultrasounds. For many parents the grief is overwhelming and many of the experiences after giving birth further exacerbated their grief.

'That's when my floodgates came, I just remember screaming, not screaming out loud but wailing just the grief the outpouring of grief' (Hannah)

'I was quite teary (...) overwhelming sadness, crying, I didn't eat, couldn't eat for two or three week and then it's just that terrible loss and then seeing pregnant women and other people having babies, it was terrible and I remember lying in bed thinking I don't wanna get out, I just don't wanna get up, just don't want to' (Isobel)

Four out of five mothers spoke about the hard experience of being around other women giving birth in the hospital and the sound of newly born babies whilst they were in the process of giving birth and spending time with their stillborn child.

'The hard thing was hearing other women in labour and babies being born and being on the same floor as them was really hard, it would have been nice to be away from the birthing rooms' (Laura)

'It was on the delivery ward and there is a room right down the end of that ward and around the corner which is obviously where you go but every time I had to go to the toilet and after she was born when I had a shower, there was women in there in labour, I found that particularly tough (...) I found that a bit hard coz it was right amongst the others.' (Isobel)

Laura also talked of the struggle of her milk coming in,

'That next week I felt shattered, I was sore, my milk was coming in so every time somebody hugged me it felt like ouch and I ended up getting an infection and yeah just felt a bit miserable as well' (Laura)

Parents from this study did not only share about their grief for the child they had lost but also the grief for the life that they had prepared for and lost.

‘For us the loss was much more about the life we had imagined, not the specific individual but the future we envisaged, what our next year would be like, the relationships with our friends who also have kids, our parents becoming grandparents. It was the loss of a dream, our future, rather than of a specific person’ (Michael)

‘People try to understand and be sympathetic and supportive to you but people think you didn’t know the child but it’s not just that, you’re saying goodbye to your hopes and dreams and how you saw your life to be and a lot of people don’t really get that’ (Sophia)

These extracts illustrate the complex grief that parents of children face. Not only is their grief for the baby that they have lost but grief for the life they lost when their baby died. Alongside these feelings of grief comes the pain of seeing other parents with newborn babies, and for mothers the pain of labour, and the biological and hormonal after effects of giving birth. One of the major challenges for parents is facing a future that is not the one that they planned and this challenge is mentioned in a number of previous articles. Parents not only lose their baby but they also lose the sense of joy and celebration at the time of birth, their feelings of parenthood, and the hopes and dreams for their future (Downe et al., 2013; Lindgren, 2014; Malm et al., 2011; McCreight, 2008; Samuelsson et al., 2001). Samuelsson and colleagues also found that in some cases it was not until parents did have a live born child that they realised just how much they had missed out on with their stillborn child (Samuelsson et al., 2001). The grief of having a

stillborn baby can be heightened by the physical and biological reminders of their lost baby. For mothers, their milk comes in and their hormones are changing. For mothers and fathers being confronted with other babies and going home to a house prepared for the arrival of a new baby is particularly hard and a reminder of their great loss (Downe et al., 2013). Murphy & Thomas (2013) and Bremborg & Radestad (2013) found that over the parent's lifetime there may be moments that resonate with them that may remind them of the stage that their child would be at in their life. The reminders for parents of their baby continue throughout life and grief can heighten when these reminders occur.

Coping

Coping with the grief was a hard task for all parents; however for some parents this task was made somewhat easier by doing specific things that made them feel better. The most common coping strategies amongst this sample of parents was talking, visiting the grave of their stillborn baby, and keeping busy. For four out of the eight participants talking was a great way of coping, whether it was to their partner, to their family, to their friends, to a support group, or to God they found that getting their feelings and thoughts out of their head was helpful and having those supports to talk to was also helpful. Two out of eight participants said visiting the grave was helpful, it felt calming and peaceful and nice to be close to their baby. Four out of eight participants also said that it helped to keep busy with work or activities, two of the parents also said already having a child was a good way to keep busy and get going with life again.

'Talking I think was the biggy, I think, I'd talk to one particular best buddy who was probably thinking oh my God but different things in my life where I have had dramas I talk, I talk to friends and family and that's how I seem to get through it' (Isobel)

'For me it was just going to her grave in the first month, maybe a little bit longer, I used to go almost every day, it was the most calm place for me, and just sit there, I just found it very, very peaceful.' (Sophia)

'Having a two year old son at the same time, it made you get on with life rather than sit around and grieve and contemplate (...) you had a busy toddler to look after and his birthday was two weeks after so we had that to plan a bit, so life still had to tick along so that was actually helpful that it wasn't our first baby and that we still had a son who we needed to keep looking after and he kept us busy.' (Laura)

For some parents part of the healing from the stillbirth occurred when the life that they had envisaged with their stillborn baby was fulfilled with another baby. This does not mean to say that their stillborn child could be replaced easily with another baby but as said above parents grieve for their baby but they also grieve for the life that they have lost and sometimes that grief can be fixed in time by fulfilling their hopes and dreams for their future and their family.

'My husband was saying he didn't want any more children and I did so that was pretty ugly there for a while (...) then I fell pregnant again twice and miscarried and he said there would be no more which I wasn't happy about but sold all the baby gear and dadadada, low

and behold this one came along and I think he was just meant to be coz he certainly wasn't planned and as soon as he was born all that hurt that I had carried was gone, that was gone and I knew that was it, I felt complete really. I remember thinking if I don't have another baby I am never gonna get over this ... life and time is a great healer but he was the biggest healer and he was born two years later, just about two years later, so that was the biggest healer really, another baby.' (Isobel)

The pain and grief for parents of stillborn children is multi faceted and coping with these feelings can be difficult and take a lot of time. Participants of this study believed that time was a great healer but also that there were other means that helped them to resolve their grief. Whilst these were different for each participant, it is helpful to know that there are positive things parents can do that may help them to cope with their grief and move forward with their life.

Bremborg & Radestad (2013) suggest that there are things that parents can do to continue a bond with their baby and not only remind them of their baby but help them to socially incorporate the baby in to their future. Bremborg & Radestad (2013) discuss five different types of memorialisation in terms of coping: internal memorialisation, home based memorialisation, traditional grave visits, extended memorial rituals, and alternative activities. Parents in this study were most likely to take part in internal memorialisation, home based memorialisation, and traditional grave visits. Internal memorialisation is where parents think of their stillborn baby but they do not often talk about them to anybody else, they often feel sadness when

thinking about the baby but do not wish to share that with anybody else. In this study it was fathers who seemed to engage in this sort of coping. Home based memorialisation is where parents share their stillborn child with their family. Homes often have pictures and symbols of the stillborn baby and parents often talk about their stillborn baby and sometimes reminisce with photos and tokens they have of their baby. The majority of parents in this study took part in coping methods such as these. Traditional grave visits are where the parents and family visit the grave of their stillborn baby and often take flowers or gifts for the child. Grave visits were another common way for parents in this study to cope with the loss of their child. Another study looked at support and coping in parents of stillborn children and found that the top three supports for parents were the same, however there were differences in the ordering of these supports. For mothers their top support was their children, a new baby, and then their partner and for fathers their top support was their partner, their children, and then a new baby (Erlandsson, Säflund, et al., 2011). Similarly to the current research having a new baby helped parents to heal and to feel complete. Whilst having a new baby does not fill the place of the stillborn baby it allows parents to feel fulfilled and to have the future that they had hoped for.

Fathers' Perspectives

There is an imbalance in the research with most international literature surrounding stillbirth pertaining to mothers'. Therefore, as mentioned earlier, this study aimed to take a stronger interest in the perspective of fathers who have stillborn children. In order to clarify, the views and experiences of the fathers have not been separated from the mothers in the themes above

as many of the mothers and fathers had similar experiences and perspectives. However, the subthemes illustrated and discussed below are additional topics that were specific to the fathers' stories and had a major impact on the fathers'. Three out of the eight participants in this study were fathers to stillborn children and their contribution was invaluable. Whilst mothers shared parts of their partners experience the firsthand accounts gave valuable information. Between the three fathers interviewed in this study they had actually experienced five stillbirths altogether.

Perception that the father's grief is not as bad

Whilst all three of these fathers were extremely upset at the news that their baby was stillborn there was the assumption made by both mothers and fathers in this study that the mother's grief was more severe than the father's grief. Fathers believed that they needed to be strong for their partners because their partner's pain was worse than their own. Five out of the eight participants in this study made some reference to the difference in the pain and grief between mothers and fathers, the excerpts below are just two examples of this perceived difference.

'Whatever I was feeling I just assumed she was feeling ten times worse (...) whatever grief I was feeling I didn't feel I could share that with [partner] because I felt like I would be burdening her when her grief would be greater than mine and I love [stillborn daughter] with all my heart like all my kids I don't imagine being able to love her anymore but somehow I thought her grief would be greater ya know coz she carried [stillborn daughter] for nine months so you make that assumption that, that naturally she would be feeling a lot more.' (Shaun)

'I hate to say it, I think men get over it probably a bit quicker (...) but a man doesn't know what it feels like to be pregnant and so there's all of that, that goes on too and you try to figure it all out and after a mother has a child a, sort of, maternal thing kicks in and you're in that mode, it's a hard thing, I think it's different, I'm not saying they don't grieve but they do it much differently, I think they would grieve for the loss of their child but they don't go through all those other emotions of the mother who is carrying the child, the hormones.' (Sophia)

While it was common for both fathers and mothers in the study to think that the pain and grief of mothers would be greater than that of fathers, I highlight a quote from Shaun's excerpt above where Shaun acknowledges that he could not have loved his baby any more but somehow he thought his partner's grief would be worse. I also quote the other fathers stories of grief which illustrates the strength of their grief.

'I felt like I would be burdening her when her grief would be greater than mine and I love [stillborn daughter] with all my heart, like all my kids, I don't imagine being able to love her any more, but somehow I thought her grief would be greater.' (Shaun)

'I was sort of manic and obsessive a few weeks afterwards, being busy and doing stuff all the time and obsessive thinking about what needs to doing and I could observe at the time that it wasn't normal and it was my grief response but I couldn't stop it' (Michael)

'I was crying and crying and I'm not a crier but when you're holding this baby, that really you're expecting to make baby noises you no coz it's so pink, and I'm quite a strong person but just this wee pink baby that you're expecting to take a breath and it wasn't, it was just overwhelming, I've never cried like it' (Jacob)

'My husband sat there balling his eyes out, he's not a very emotional man, you know what I mean, he's very closed but he sat, the whole time he was there he sat there crying and I sat there comforting' (Hannah)

There is a perception by both mothers and fathers that the pain and grief is worse for mothers. However, it may just be, as Sophia said, that the pain and grief is different between mothers and fathers. Literature states that the perceived difference in grieving is a common problem that many parents of stillborn children encounter (Samuelsson et al., 2001; Bonnette & Broom, 2012; Stinson, Lasker, Lohmann, & Toedter, 1992; Wallerstedt & Higgins, 1996). Stereotypical traits of men such as stoicism, strength, and inexpressiveness can lead to the assumption that stillbirth affects women more than it affects men, however, previous literature shows that fathers can emotionally struggle to cope with stillbirth just as much as mothers (Bonnette & Broom, 2012). However, this may be concealed by a need to cope with the loss in a masculine way, a desire to be a strong supporter and protector for their partner during this distressing time, and a belief that it is their job to handle the practical details so the mother does not have to (Samuelsson et al., 2001). However, by prioritising other things instead of themselves, fathers found they could become frustrated as they suppressed their emotions, and in turn felt

they received less support than their partner did (Samuelsson et al., 2001; Wagner et al., 1997). However, by internalising their emotions and showing reduced emotional attachment towards the stillbirth it suggests to others that the father is grieving less than the mother and that the focus of care and support should be directed towards the mother. Thus, the father can feel as if their grief has been disregarded and continues to internalise his grief and cope in the stereotypical masculine way, reinforcing the notion that fathers experience less grief and therefore need less support. Literature also supports the notion that mothers and fathers often have different grieving and coping styles (Avelin et al., 2013; McGreal et al., 1997; Samuelsson et al., 2001; Wallerstedt & Higgins, 1996). Fathers are more likely to internalise their grief or to grieve in private which, as illustrated above, can add to the perceived difference in grief (Bonnette & Broom, 2012; Samuelsson et al., 2001; Stinson et al., 1992). Fathers stories from this study support the premise that fathers are more likely to grieve in private as they shared that they often grieved or had a 'wee cry' in their cars while commuting or just when driving by themselves. Literature also suggests that fathers move through the grieving process at a faster pace and may be another reason why both parents' and family and friends perceive that the mother's grief is worse. (Badenhorst et al., 2006; McGreal et al., 1997; Samuelsson et al., 2001). Multiple pieces of research suggests that it is common for mothers to feel guilt for their body's failure, for disappointing their partner and perhaps wider family, and from their point of view, ultimately killing their baby (Cacciatore et al., 2013; Cacciatore, 2010; Kirkley-Best & Kellner, 1982; McGreal et al., 1997). However, research shows very few fathers report this feeling and could suggest why it takes more time for mothers to move through the grieving process than fathers (Badenhorst et al., 2006). The distribution of support is commonly directed towards the

mother after a stillbirth and often the father can feel as if their grief is less important. In today's world, fathers, although not physically attached to the baby like the mother, can be just as involved and excited for the arrival of their baby as the mother. I believe there is a discrepancy between the perception of grief and actual grief. While previous literature suggests that the mother's grief is worse and mothers and fathers of this study also perceived the mother's grief to be worse, the actual statements from fathers themselves and mothers' statements about their partner suggest that the initial grief period is similar between mothers and fathers. Mothers and fathers may grieve differently but this does not mean they do not grieve equally. A father's grief can be just as strong and this is shown in the next subtheme.

Fathers are emotional

Although many participants believed the mother's grief to be worse than the father's grief, fathers were extremely emotional over the loss of their child, both fathers themselves and mothers sharing their partners experience reported that fathers shed many tears over the loss of their baby. This was not just an initial reaction, two fathers from the study shared that they continued to grieve privately in their car while driving and they often had a 'wee cry' whilst commuting. One father believed that he would never stop grieving for his stillborn baby he would just learn to cope with it better. Whilst crying is not the only way that emotion can be expressed, it was the most common sign of emotion in parents' stories. The excerpts below have been quoted above; however, I have reused them as they illustrate strongly the emotion attached to the loss of their stillborn baby.

'My husband sat there balling his eyes out, he's not a very emotional man ... he's very closed but he sat the whole time he was there, he sat there crying and I sat there comforting because I don't know why, I just thought he was sitting there balling his eyes out and I just sat there and I was drugged up to the nines.' (Hannah)

'They kept popping back in to see if I was alright and I was crying and crying and I'm not a crier but when you are holding this baby that really your expecting to make baby noises, you know coz it's so pink, and I'm quite a strong person but just this wee pink baby that you're expecting to take a breath and it wasn't, it was just overwhelming, I've never cried like it.'
(Jacob)

One father reported to praying and hoping during their partner's labour that the doctors had it wrong; there was a small amount of denial that doctors could not be right and that the baby would come out crying.

'There was almost a split second that when she first came out that the fact that she wasn't alive wasn't real, the whole time when she came out ya just wanted to think that they got it wrong (...) there was some third world in my head where she came out and I was thinking oh they got it wrong, they had it wrong you know, I just wanted them to have had it wrong.'
(Shaun)

These excerpts show that the grief and emotion that fathers feel over the loss over their baby is extremely strong. Fathers of today's generation can be more involved in the pregnancy process

than ever before. Whilst this allows them to become more attached and excited for the arrival of their newborn, the death of their baby can leave them feeling shocked, angry, upset, and devastated; all of the emotions that the mother would feel during this turmoil. Literature supports fathers of today's generation as many studies show that fathers can be just as attached to their baby as mothers and therefore go through a similar grief process as mothers (Badenhorst et al., 2006; McCreight, 2008; Weaver-Hightower, 2012). An exploratory study asked fathers to rate their grief at the time on a scale of one to ten, one being no grief and ten being severe grief. Fathers who lost their baby during the first trimester had a mean grief score of 3.5; however, fathers who lost their baby in the second or third trimester had a mean grief score of 9.85 (Wagner et al., 1997). Thus showing, that the feeling of loss is severe for fathers and could not be much greater; just because fathers are not physically attached to the baby does not mean they were any less devastated than the mother when it died. The study also asked about fathers current grieving and coping and found that the majority of fathers were still grieving for their lost baby. Whilst their grief had reduced fathers stated that they expected to grieve for their baby for the rest of their life (Wagner et al., 1997). This was also a theme that came out of the current study and was discussed above.

Giving birth

A common theme throughout the stories of the fathers was the affirmation that the vaginal delivery seemed to have more dignity. While mothers mentioned their birth in terms of the processes that occurred, most did not elaborate on whether they would have preferred a

caesarean section or vaginal birth. One mother did report that she did not want a caesarean section as she did not want to be in pain afterwards. One father also mentioned that his wife, although they were not given an option, she also would not have wanted to be in pain afterwards as she is a very active person. Compared to mothers' stories fathers' seemed to have a more emotional connection with the way their baby was born. Whilst one father originally thought the process of giving birth vaginally to be somewhat cruel, going through that process allowed him the experience of being there for the birth of his child; a caesarean section would have taken this special experience from him. At a time where experiences with your baby are limited, this experience seemed to be an important one. One of the fathers who had experienced two stillbirths with two of his children had been through two different experiences of giving birth, one was a caesarean section and the other was a vaginal delivery and he believed, from his perspective, that the vaginal delivery was better as he was able to be there for the birth.

'In my head I just assumed they would cut the baby out and that would be it and I guess the real clanger came when they told us we actually had to go through the whole process of delivering the baby, so that was sort of difficult to understand really , when you had already gone through all that trauma and they're gonna make you go through a whole lot more (...) but I guess the benefit, well there wasn't a benefit but giving birth naturally, for me anyway, and I can't speak for [partner] but the minute [stillborn daughter] was born there was just a wee thing there that suggested that she, ya no, when she came out that she was like any other one of my kids and the instant they come out ya just love them like ya can't imagine, like you

haven't known them but they're yours and it's a strange thing I guess (...) but I don't think I would have had that moment though if she had been C-sectioned.' (Shaun)

'The birth is very real and in terms of that whole grief process I think I manage better and I did have some emotional issues with the second one having to be delivered by caesarean section then waiting in this room for them to bring me this baby, I think I cope better watching the delivery and knowing what's going to happen.' (Jacob)

Fathers seemed to have a strong connection to the way the baby was born. Vaginal birth seemed to give fathers a unique connection with their baby; an extra memory of their baby which is special during a time when memories to be made are minimal compared to the amount they intended to make throughout their baby's life. Two of the three fathers in this study originally believed that their partner giving birth naturally was traumatising; going through all of that pain and having no reward at the end. However, after going through that process they realised that their partner giving birth naturally was more dignified. It also gave them the opportunity to go through that experience with their partner and have the opportunity to be involved in the birth of their baby and to be there at the miraculous moment when their partner finally gave birth to their baby. They believed that this was an important experience to go through and preferred this method of delivery over a caesarean section. Samuelsson et al. (2001) supports this finding and adds that fathers also believed that during this time they played an important role in supporting their partner through this experience. After the experience of labour and birth research shows that fathers found it natural to see,

hold, create memories with their baby, and have tokens of their baby to take home with them. Many fathers enjoyed and were grateful to have these experiences with their baby and spent much of their time trying to remember every inch of their baby's body and appearance (Cacciatore, Erlandsson, & Radestad, 2013; Samuelsson et al., 2001; Weaver-Hightower, 2012). This idea is supported by the fathers in this study who naturally wanted to see, hold, and create memories with their baby. Two of the three fathers in this study said their baby was perfect and just looked like it was sleeping.

Conclusion

The themes above have been derived from the interviews with the participants in this study. These themes are important as the voice of the parents and the richness to their stories have provided further insight into the experience of stillbirth within the New Zealand context. The parents' experiences have not only been a starting point for further research within New Zealand but they have added further depth to international stillbirth literature. Their individual and combined experiences have alluded to themes which have been compared and contrasted showing similarities and differences with reference to international literature which has been discussed above in this chapter. Thus showing, this research has uncovered some interesting themes that can be researched further both internationally and within the New Zealand context. The themes will be discussed further in the following chapter along with recommendations and future research opportunities.

Chapter 5: Discussion and Concluding Thoughts

Introduction

This research aimed to explore, understand, and describe the experience of parents who have a stillborn child in New Zealand. By asking about the parents experience and understanding their perspective we are able to understand how the care, support, and information given to these parents, from both healthcare professionals and their own community, are perceived.

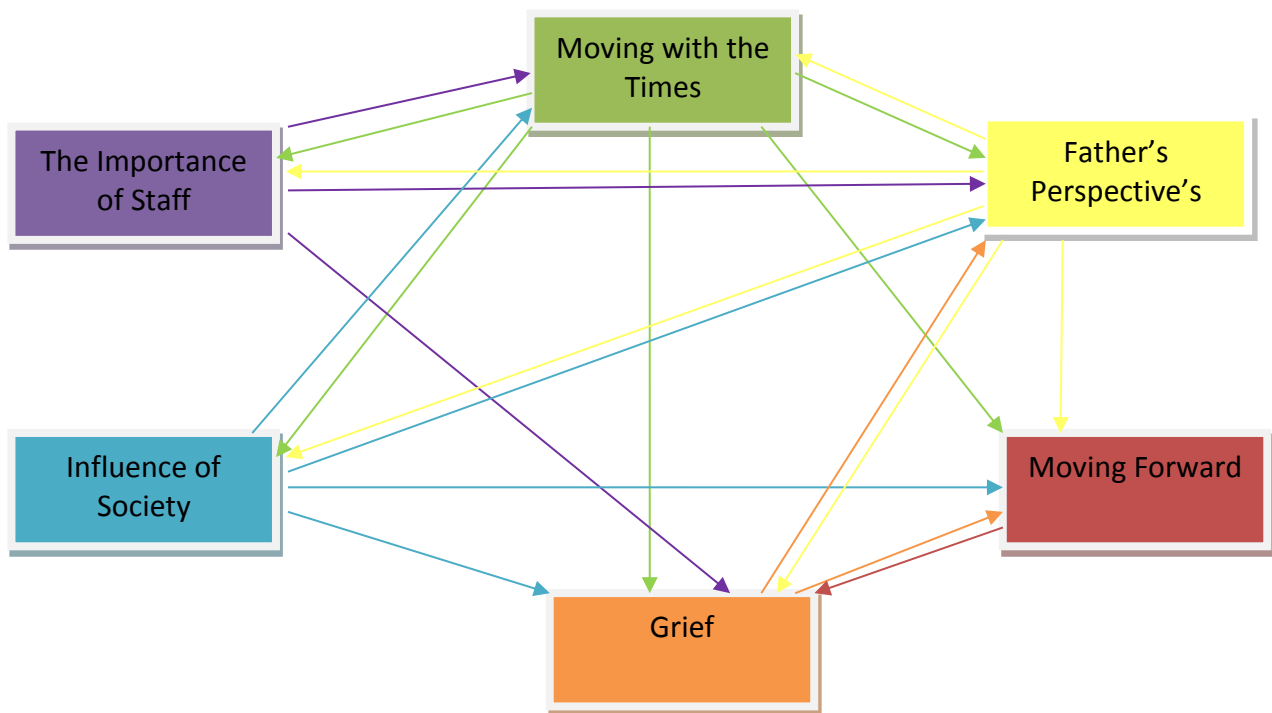
Understanding their perspective is important because how we interact and communicate at this time can have long lasting effects on their life. By gaining the perspective of the parents we are offered helpful information to be able to evaluate care, taking into account aspects that can lead to negative outcomes for parents, increasing the chances of positive adjustment.

The literature review yielded a wealth of international research surrounding the needs, wants and outcomes for parents who have a stillborn child. However, research from the parent's perspective in New Zealand was limited. Whilst research from other countries is still valuable and can be generalised to the New Zealand context, it would be beneficial to have research being conducted within New Zealand in order to have a true understanding of the experience of stillbirth within the New Zealand context. This study has begun this process.

The participants in this research all willingly shared their stories and experiences with the researcher and each described different scenarios and actions that changed their experience, both for better and for worse. By conducting this research and understanding and describing the parents' experiences through the use of the parents' own words we now have an indication of how stillbirth and the care and support surrounding a stillbirth may affect parents within the New Zealand context. Acknowledging a small sample size, the data is rich and descriptive and is a helpful beginning to inspire other avenues of future research, inform and educate healthcare professionals, and further enhance the care received by parents of stillborn children.

From the stories and experiences that the parents shared with the researcher six themes were identified. While each theme is different and can be separated as an individual theme they are also interlinked with each other. This interconnectivity means that if care is good in one area then it is likely that this good care will reflect and positively impact other areas of care and recovery that are interlinked. However, on the other hand, if one area of care is poor then this may impact the rest of the parents' care and also their recovery from the stillbirth. Figure one shows the interconnectedness between the themes and shows which themes intertwine with others. The paragraphs below will explain in further depth the interconnectivity between each of the themes.

Figure 1: Intertwining of themes



Interconnectivity of themes

Moving with the times

Most themes reciprocate and influence each other; however, the theme 'moving with the times' was the most influential on other themes. This shows that change in practice from immediately taking the baby away from the parents to encouraging parents to see, hold, and create memories with their baby has had a significant impact on the care and recovery of parents during and after a stillbirth. All parents in this study were glad to have met their baby and have the opportunity to fulfil their needs as a parent. This change in practice allows parents to create memories with their baby that they get to keep for the rest of their lifetime. This affects the way that parents grieve, cope, and move forward with their life, thus, influencing to

other themes presented in this research. The changes in practice also increase the depth of involvement and care that healthcare professionals are required to provide for these parents. The process of a stillbirth is no longer a quick ordeal where parents are taken to hospital to give birth, have their baby taken from them, and then discharged with the encouragement to have another baby. Currently, parents are encouraged to mourn the loss of their child and engage in memory making activities to substitute for the lifetime of memories that they have lost. However, the responsibility for ensuring that parents have the opportunity to do this in a comfortable and healthy manner falls to the healthcare professional that is caring for the parents. Thus the theme 'moving with the times' has a significant impact on the role of healthcare professionals. The change in practice also changes the way that the communities that surround and support parents of stillborn children approach and think about the event of a stillbirth. The opportunity for parents to take their stillborn babies home and hold services for them increases awareness of stillbirth and the extreme grief that parents experience for their lost child. Therefore, 'moving with the times' affects a fourth theme in this research. Last but not least, it affects the involvement the father has with his baby by giving him a chance to intimately know his child. In previous generations, both the father and the mother had no opportunity to meet their baby. However, through pregnancy the mother already shared an intimate bond with her baby through their physical connection. Today, parents have the opportunity to get to know their baby in much greater detail before they are born through the use of modern technology. However, after interviewing the fathers in this study, meeting the baby after it is born provides an intimate connection like no other; a connection that can only be felt through meeting their baby. Whilst evidence contrasting about the positive and negative

effects of engaging in such activities, most parents from previous literature, and all parents from this study, believe that seeing, holding, and engaging in memory making was positive and constructive for their grieving, coping, and healing. Participants from this research all believed that engaging memory making activities, including taking the baby home and holding a service for their baby, contributed positively toward their experience. Therefore, this research is supportive of the current practice to encourage seeing, holding and engaging in memory making activities.

The importance of staff

The theme ‘the importance of staff’ has a significant influence on three other themes: ‘moving with the times,’ ‘grief’ and ‘moving forward.’ As discussed above, the change in practice from immediately taking the baby away from the parents to encouraging parents to see, hold, and make memories with their baby has had a significant impact on the role of healthcare professionals. This change gives healthcare professionals power and control over the way these modern practices and care are provided, thus, the themes ‘moving with the times’ and ‘the importance of staff’ have a reciprocating influence on each other. Whilst the modernisation of practice associated with ‘moving with the times’ can positively influence the parent’s grief, coping, and the ability to move forward with their life, the theme ‘the importance of staff’ can have the same positive influence or a counter active influence depending on the quality of care given by the healthcare professional. Now days caring for parents of stillborn children involves more authentic and empathetic care and support and a genuine concern for the parents wellbeing. Healthcare professionals need to understand that these factors impact on parent’s

experiences. Healthcare professionals who do not provide such care can have a detrimental effect on the parents' current and future wellbeing. However, those healthcare professionals who do give empathetic and authentic care and who also give as much time as possible to allow parents to make as many memories as they feel necessary can positively impact the 'grief' of those parents and their ability to 'move forward' with their life (Downe et al., 2013; Lisy et al., 2016; Radestad et al., 2011). In a similar way to findings from previous research studies, parents from this study can testify to the effect that genuine and ingenuine healthcare professionals can have on their care. Without healthcare staff who convey genuine concern for the welfare of these parents, parents may forego the opportunity to create memories that may help them to grieve, heal and to commemorate their baby and have tokens of their baby that they could treasure for the rest of their lives (Downe et al., 2013; Kavanaugh & Moro, 2006; Lisy et al., 2016; Radestad et al., 2011; Trulsson & Rådestad, 2004). Ensuring that both mothers and fathers engage in these activities, to the level that they are comfortable with, and create and maintain that instantaneous bond that a parent and their child have as soon as they are born is crucial to the well being of the parents. Healthcare professionals play a large role in encouraging parents to take these steps and thus the theme 'the importance of staff' significantly influences the themes 'moving with the times,' 'grief,' and 'moving forward.'

The influence of society

The theme 'the influence of society' affects three other themes: 'moving with the times,' 'grief,' and 'moving forward.' The change in practice not only encourages parents to see, hold, and create their own memories with their baby but they are also encouraged to take their baby

home and hold a service for their baby. This means it is likely that close family and friends of the parents may have a chance to meet the baby and attend a service for them. As noted previously, international research states that parents of stillborn children can encounter stigma, exclusion, and awkwardness among their community as others do not understand the grief of a stillbirth. Fathers', from previous research, have also stated that they feel they do not receive as much support as mothers do from their social circle and that they feel their grief is less validated than mothers' grief (Bonnette & Broom, 2012). However, having the opportunity to be involved in the process of grieving and farewelling a stillborn baby may allow family and friends of the parents to be more supportive. When parents of stillborn children have a supportive and caring network of family and friends, the well being of the parents is significantly better than those parents who do not have that support (de Montigny et al., 1999). In previous studies parents who had a stillborn child reported lack of support from their social circle. People did not understand the parents feelings of loss and grief and if they did they just did not want to talk about it (Lewis, 1979; Stringham et al., 1982). Recent studies have reported that support does not only come in the form of direct emotional support but that it can come in other forms as well such as: material support, practical support, and socialising (Kavanaugh et al., 2004). These other forms of support that friends and family provide show parents that they care and that they are thinking of them and their lost baby. Whilst not all people have the abilities to provide the important emotional support needed by these parents, offering other forms of support shows parents that they do have a wide network of support which can positively affect their mental and overall wellbeing. In the current study both mothers and fathers reported good support from their friends, family and wider community including strong

emotional support and the other forms of support mentioned above. Parents of stillborn children who do not have good support and care from friends and family are more likely to encounter problems with anxiety, depression, or post traumatic stress which affects 'grief' and their ability to 'move forward' with their life and therefore counteracts the positive opportunities discussed in the theme 'moving with the times' (Cacciatore et al., 2009).

Moving forward

The theme 'moving forward,' is strongly influenced by other themes but affects only two other themes itself: 'grief' and 'the fathers' perspectives.' The ability for parents to move on with their life is affected by the rituals they did or did not take part in after their baby was born, by their grief, and by the influence that their community has had on their grieving and coping. For many parents, both in this study and in previous literature, moving on has not meant leaving the stillborn baby in the past but continuing to include the baby as a member of their family. The ability to include the baby as a member of the family is aided by the memory making that may have occurred after the baby was born. Memory making not only allows families to remember the stillborn baby and what they looked like but allows them to have special mementoes of their baby. Having these mementoes allows parents the opportunity to display items of the baby's in their home or to have a memory box full of items special to the baby that may be brought out on special occasions such as their birthday. Most of the parents in the current study engaged in memorialisation with their family through the use of mementoes which ensured the baby would continue to be included in their life. Whilst fathers from this study also engaged in such memorialisation they were more likely to engage in internal

memorialisation where they would think of their baby often and feel sadness about the loss of their baby but they did not feel the need to share or talk about that with anybody else. Two out of the three fathers who participated in this study mentioned crying in their car by themselves. The ability for men to hide their emotions about the loss of their baby may provide a sense of comfort to both themselves and their partner. Putting up a masculine front may help them to feel as if they are coping and allow them to be the strength and stability that their partner needs during such a traumatising time. However, engaging in memorialisation in any form and including the baby in their everyday life can help parents come to terms with the loss of their baby and to feel comfortable moving forward with their life (Bremborg & Radestad, 2013). As parents move forward with their life it can enable them to feel better which helps them to further resolve their grief. In doing so, the further resolution of grief can have a reciprocating effect and can help parents to once again take a step forward with their life. The reciprocating influence that 'grief' has on moving forward will be discussed further below in the grief section.

Another way parents of the current study found helpful in moving on, that also assisted in their grieving, was being around their children or putting effort into becoming pregnant again and having another child. As mentioned earlier, parents are not only grieving for their lost child but they are grieving for the life that they have also lost. For parents who already have children they have lost the opportunity to extend their family and have siblings for their other child/children. For parents who are having their first child they have lost the opportunity of starting their family and giving their parents and siblings the opportunity to have a grandchild or a niece or nephew. They miss out on the activities they planned to participate in with their

child and all the parental duties they had looked forward too. For parents, whether they have already had a child or not, they are grieving for both their lost baby and their lost future. Whilst parents from this study found it difficult to be around other parents' babies and young children they found it helpful to be around their own. Already having a child/children meant parents had priorities other than themselves to focus on, thus, their children kept them busy and naturally kept them moving forward with life. For both parents who did and did not already have children, they found having another baby healing. Although their new baby did not replace the hole in their heart that the stillborn baby left, it did fulfil their needs and the hole they felt in their life. When their new baby arrived happy and healthy they found that they felt healed of their grief and that the future they had wished for had been restored.

Grief

Grief is a theme that was affected by all other themes; it is affected by the rituals parents partake in after the baby is born, it is affected by the way healthcare professionals support and care for parents during their time in hospital, it is affected by the way society and the parents community react to the news of their stillbirth and whether they have support and care in their time of need, and as discussed above, moving forward often has a positive effect on grief and can help parents to heal. However, it only has influence on two other themes: 'moving forward' and 'the fathers' perspectives.' The grief of parents of stillborn children is complex, while they are grieving for the baby they have lost, they are also grieving for the future they have lost. Both, mother and fathers who participated in this study shared their experience of constant and overwhelming sadness, being emotionally and physically drained, and their intense outpouring of grief. Whilst the expression of these emotions may have been different, with

mothers' display of grief more overt and fathers' more covert, they both shared experiences of a sudden and sickening loss and the continual grief that followed. Coming to terms with that grief and loss and learning to cope is difficult but many parents mentioned that engaging in certain activities was helpful. For some parents it was taking time to remember their baby by visiting the grave of their baby, for others it was talking about their baby and their feelings, and for others it was the ability to keep busy. As mentioned above in 'moving forward' the memorialisation and inclusion of the baby was significant part of learning to move forward, as the two themes are so closely interlinked it is also a large part of learning to deal with the grief. Including the stillborn baby in their everyday life by having mementoes of the baby to show, share, and talk about with family and friends meant that although the baby was gone it was not forgotten. Having the ability to maintain a relationship with their stillborn baby aided the healing of grief and therefore assisted parents to feel comfortable moving forward with their life.

As mentioned in the experiences chapter the grief of parents of stillborn children is complex and multifaceted; they grieve for both the loss of their baby but also the loss of their future that they had envisaged for themselves. Whilst continuing to include their stillborn baby in their life and continuing that bond with their baby is seen as helpful a number of the parents from this study found having another baby healing. Whilst some of these pregnancies were not planned, of the eight participants in this study five proceeded to have at least one other child after their stillborn. Parents commented that these children unknowingly helped them to heal. While parents commented that their new children did not replace their stillborn child, these children

fulfilled a dream that was taken from them with their stillborn baby. Having another baby helped them to get past their grief and helped them to feel complete again.

Fathers' perspectives

The subsection of 'fathers' perspectives' is interlinked with all other themes as it is their experience that links these themes. Just like mothers, fathers experience all of the other themes as a parent of a stillborn baby. Fathers, whilst not physically going through the process of giving birth, have a similar experience to mothers; they engage in memory making activities, they have similar encounters with healthcare professionals, they grieve for the loss of their baby, and they too have to learn to cope and manage their grief so they can eventually move on with life. Their experiences have been included in the themes above and how they each interlink with each other and therefore have already been discussed in the above sections.

As illustrated, the above sections all influence one another, thus, it is crucial that all parents have the best care and support at each stage of their stillbirth. In providing quality care at every opportunity to parents of stillborn children it is more likely to have a positive impact on other aspects of their experience and therefore reduce the likelihood of negative outcomes.

Further Considerations

Upon analysis of the data pertaining to the theme 'the importance of staff' there showed a difference between the care received by parents who had their LMC caring for them and

parents who had the hospital staff rostered on that day caring for them. Throughout the literature read prior to and alongside this research no reference was made to the difference in care provided to parents by different healthcare staff. Maybe this is a difference that only occurs within in New Zealand due to the way our maternity and healthcare system works, however, this finding warrants future research as it may provide answers about how care can be improved and how differences in care can affect the outcomes of parents of stillborn children.

Parents of stillborn children often find that great support comes from those who have been through their own perinatal death (Cacciatore, 2010). Whilst parents from this research also stated that they received good support from others who had been in a similar situation to themselves they also commented that the support and care that they received from their family, friends, and larger community was also relatively good. Whilst there may have been some ambiguity or awkwardness in not knowing what to say or the repetition of what felt like meaningless platitudes, all parents in this study believed that they had good support from their personal networks. This suggests that communities within New Zealand may be more tolerant and understanding of stillbirth and the grief associated than other countries. However, with such a small sample size this conclusion cannot be generalised to New Zealand as a whole.

Another difference that was encountered in the current study was the differences between partners who did not share the same culture. Throughout the literature read previous to and alongside this research about the challenges stillbirth can create in a relationship it was

suggested that differences in grieving and coping were the main reasons behind these relationship challenges (Avelin et al., 2013; McGreal et al., 1997; Samuelsson et al., 2001; Wallerstedt & Higgins, 1996). However, within the current study two out of three couples who were in a cross-cultural relationship had differences of opinion when it came to rituals they should and should not participate in after their baby was born. The number of participants in this study is small and therefore the data cannot be generalised, however, New Zealand is a multi cultural society and has large numbers of cross-cultural relationships. This finding is worthy of future research in order to decrease the difficulties that cross-cultural partners may face if they were to have the unfortunate experience of becoming parents to a stillborn child.

Literature has suggested that many parents who engage in memory making activities experience temporary increases in mental health problems such as depression, anxiety, and post traumatic stress disorder during a subsequent pregnancy (Hughes et al., 1999; Turton et al., 2001). Whilst the current study did not measure any mental health symptoms, all of the parents participated in memory making with their stillborn baby but none of the parents mentioned any significant mental health issues. Some of the participants reported increases in anxiety but not to the level where it was a concerning or long lasting issue. This study does not show results that support the notion that memory making can increase temporary mental health problems in a subsequent pregnancy. However, it does suggest that increases in anxiety would be a normal reaction during a subsequent pregnancy as not only are parents reminded of the baby that they have already lost but they are overly aware that not all pregnancies end in healthy, happy babies. Further study into increases in mental health symptoms such as anxiety during a subsequent pregnancy after a stillborn child in New Zealand may provide more

substantial evidence to support or negate the claim that memory making increases the likelihood of temporary mental health problems in a subsequent pregnancy. However, the most important part of future research in this area would be the ability to understand this temporary rise in mental health symptoms so there is further support ready and available to the parents who need it.

For the fathers in this study a common theme was their emotion about the induction of labour and giving birth. Two out of the three fathers commented that after finding out that their baby had died the idea of putting their partners through the rigour of labour and birth to have no reward at the end seemed cruel. However, all three of the fathers and their partners went through the process of inducing the labour and giving birth. Upon talking to me, the two fathers that initially thought going through labour and birth was cruel found that the time spent with their partner supporting them through labour and awaiting the birth of their baby was actually a very special time. Not only was it special to be there at the birth and have that special bond and memory with their baby but the process of going through labour helped them to come to terms and cope with the situation. Being there and being a part of the process made the situation real. One of the fathers and his partner went through a caesarean section with their second stillbirth and he believed he coped much better when his wife went through labour; sitting in a waiting room waiting for them to bring him his newborn was much harder. Previous literature illustrates that many fathers and also mothers have the same feelings as the fathers in this research (Samuelsson et al., 2001). Many parents believe that a caesarean section will be quicker and less painful but after going through labour and birth they believed that it was more dignified to give birth to the baby naturally and they were happy that they did so. Whilst in

previous literature both mothers and fathers commented on the process of giving birth only fathers in this research made reference to it.

Another common theme from this research was the idea that the mother's grief is worse than the father's grief. Whilst both mothers and fathers made reference to this concept and previous literature has also found this a common theme, there are some discrepancies. Previous research has also shown that fathers grief can be extremely high, while the research did not compare fathers' grief with mothers' grief it showed that fathers' grief averaged a 9.7/10 revealing a high level of grief (Wagner et al., 1997). Alongside this, fathers from this study revealed to me that they could not have loved their baby anymore and that they cried uncontrollably while holding their baby in their arms, willing it to take a breath. The experiences and emotions that these fathers shared illustrated that their grief was strong and real and seemed similar to the grief of the mothers that participated in this study. Past research has indicated that mothers and fathers grieve at different rates which leads me to the suggestion that mothers and fathers grief may be similar after they learn that their baby has died and for a time after that (Mcgreal et al., 1997). However, due to maternal hormones, biological reminders and perhaps potential guilt they may feel about the loss of their baby, a mother's grief may stay heightened for a longer period of time, whereas, a father's grief may reduce faster as they do not have the additional difficulties, mentioned previously, to deal with. Thus, people arrive at the perspective that a mother's grief is worse than the father's grief, however, it may be that the mother's grief remains heightened for a longer period of time.

Further research would be of value to understand if this is the reason behind the differences in grief.

Strengths and Limitations

This study aimed to understand the experiences of parents who have stillborn children in a New Zealand context. As participants were recruited through a snowball method it was possible that finding a diverse range of participants may have been difficult. However, this was not the case; the study design, small number of participants, the mix of cultures, and the inclusion of both genders allowed the researcher to gain a range of valuable information. Whilst this research does not encompass all possible experiences it gives an understanding of the experiences of parents who have had a stillborn child in New Zealand, which fulfils the aim of this research.

The fact that the only method of gathering information was through interviews with parents may be seen as a limitation, however, it can also be seen as a strength. It is possible to say that the memory of participants may have faded over the years or that what actually happened was somewhat different to the way that participants remember. However, what participants perceive and remember in these situations can be very important; the things that they remember have obviously stood out to them for a reason, whether it is for a positive or negative reason. Whatever their perceived experience is, it is their perception that is important in this study. It is beneficial to healthcare professionals to understand and reflect on their caring of these parents.

A limitation of the study is the small number of participants. Whilst rich information was gathered from this research, a larger sample could provide results and information that was not identified in this study and give further depth to the themes discovered in this study. A larger study would also gather more information on cultural differences which is an important aspect of research in New Zealand as our population is multicultural.

Another limitation is the range of dates when participants had their stillbirths. The majority of the participants in this study had their stillbirths over ten years ago. While the information collected in this study is important the situation may be different for parents who have stillborns today. While hospital practices and policies may have remained somewhat similar over the past ten years, the impact of stillbirth on society may have increased through the popularity of social media. Whilst not everyone shares their experiences on social media, especially such painful and intimate experiences like stillbirth, those who do now have a much larger audience, thus influencing the information and implications of stillbirth that their wider community is exposed to. Alongside this, the opportunity for parents to share their experience of stillbirth can expose them to further support which they may not have had access too without the use of social media. Thus, the impact of social media alone may have significantly improved aspects of parents' experience and had a positive effect on the outcomes for parents of stillborn children.

The researcher would also like to acknowledge her own experience with stillbirth as a sibling. While she has shared her story in the introduction in an aim to separate her own views from

the research, it is important to acknowledge her personal experience in this area. While she does have personal experience in this area it is only through her relationship as a sibling and not as a parent. Her main goal throughout this research is to hear the voices of the parents of stillborn children and share their experiences on their behalf.

Recommendations

Based on the results above it is recommended that the opportunity to see, hold, and engage in memory making be continued. Parents have shown appreciation for this time with their baby even if they were originally hesitant to do so. Parents were also thankful for time they got to spend at home with their baby surrounded by their family and friends. Encouraging parents to take these steps has helped them grieve and come to terms with their loss.

It is also recommended that healthcare professionals, both LMC's and those who are rostered on at the time of a stillbirth be well educated on the needs of parents of stillborn children.

Some behaviours can be particularly helpful where others can be considered uncaring or even disrespectful. As shown in previous chapters parents are grateful for the genuine concern of healthcare staff. It would be opportune to have healthcare professionals who want to care for these parents to do so as they are more likely to provide the elevated level of care and support that parents of stillborn children need.

Given the shock and trauma many parents experience during and after a stillbirth it is recommended that all information given and communication had with the parents be clear and concise and given in multiple forms, verbally and visually, all the while being sensitive to their experience. With reference to information given to parents it is important to give information for further support and care for the weeks and months following the stillbirth, and also have information and support available for a potential subsequent pregnancy as parents have reported these to be particular times of struggle.

It is also recommended that fathers are offered just as much care and support as mothers receive. Although fathers may portray their grief in a different way to mothers or perhaps portray a front that seems to be less affected by the stillbirth, they can be just as emotional and grief stricken as mothers. It is important that fathers' grief not be dismissed and support remains strong for both parents throughout their grieving. This may include information and contact details for support groups specifically for fathers or referrals to a counsellor or other services specifically for men.

The above results suggest that stillbirth in New Zealand may be less stigmatised than it is in other countries. It is recommended that parents of stillborn children are supported and encouraged to talk openly about their experience with their family and community. The ability to talk openly and share memories with a supportive social network can improve wellbeing for these parents. Openly talking about stillbirth may also may help educate others and reduce stigma and uncaring attitudes from the wider community.

Future Research

Pursuing a larger study would build on to the body of knowledge uncovered from this study and potentially find additional experiences that were not found in this research. Research with a larger sample size will not only allow for a greater sample of data but also a greater ethnic range of participants. In gaining a greater ethnic diversity more understanding can be gained about the differences partners may face if they are in a cross-cultural relationship, a factor that was a feature of this research. Whilst gaining a larger sample size is important, it is still important to remain honest to hearing the parent's voices and their perspective.

Information and communication from healthcare professionals played a large role in parent's perception of care. Within this study there were different perspectives on the care given by healthcare professionals depending on the type of healthcare professionals who were primarily caring for parents. Parents with their own LMC coordinating their care reported very good care whilst those who were looked after by hospital staff reported that improvements could be made. Future research within New Zealand could investigate this area to understand better the perceived difference in care received by parents who have their LMC coordinating their care and those who have hospital staff coordinating their care. This will give a greater understanding of the types of care and support that parent's need and want during this time. In doing so, all healthcare professionals, whether LMC's or not, will be able to provide appropriate care. It is important to have a good understanding of the type of care and support that parents want and

need because it has a significant impact on parents grieving and ability to cope afterwards.

While the perspective of the parents was the only perception taken into account in this study, it may also be useful to include perspectives of healthcare professionals in future research.

Future research in New Zealand in the area mental health and social support is also recommended as previous research has suggested a link between poor social support and poor mental health. This research supports the suggestion that there may be a link between mental health and social support as all parents from this study reported good social support and good mental health. However, in this study mental health status was self reported by parents in their interviews, no mental health data was measured and collected by the researcher. Therefore, future research exploring mental health of parents of stillborn children either singularly or in conjunction with social support could provide valuable insight that this research did not find.

Whilst no difficulties with mental health were reported in this study, parents did state that their anxiety during the pregnancy did increase, however, they did not believe it reached a level where they needed help. Alongside this all parents in this study were grateful they had the opportunity to meet and spend time with their baby and would not have given up that opportunity for anything in the world. Due to the fact that there were no mental health difficulties reported and all parents wanted and were grateful to meet and spend time with their baby this study recommends the continuation of the practice to encourage parents to meet and make memories with their baby. However, further research and gathering of data surrounding mental health of parents of stillborn children may facilitate understanding of the

relationship between memory making activities and mental health issues in a subsequent pregnancy. This may then enable interventions to be provided to prevent or reduce these difficulties.

Further research will also provide education for healthcare professionals, support groups and society which will allow better care for these parents and potentially a reduction in negative outcomes after stillbirth.

Acknowledging the participants

Without the parents who participated in this research it would not have been possible. The time and stories that these parents have given to this research is a gift and I am full of admiration of these parents who willingly shared their stories with a person that they did not know particularly well about such an intimate and emotional time in their lives. Their participation is gratefully acknowledged and their experiences have not gone unheard. Hopefully this is the beginning of stillbirth research in New Zealand and future research can build upon this research and the experiences of the participants in this study.

Researcher learning

While this research was undertaken with an aim of adding to the academic body of knowledge surrounding stillbirth, the process of undertaking qualitative research was new to me and

taught me more than I expected to learn. Whilst I fulfilled my goals of carrying out systematic and authentic research, through the process of undertaking such a sensitive and emotional topic I also came to understand much more about the gift that parents gave when they shared their stories with me. Upon recruiting participants for this research I came to realise that what I was asking parents to share with me was a significant request. Not only was I asking them to relive and share their experience of one of the most traumatising times in their life but I was asking them to share that story with me, practically a complete stranger. At this point in the research I came to the conclusion that finding willing participants for this research may be harder than I originally thought, however, it was not. Whilst there was not a queue of parents lining up to share their story, there were a number of extraordinary parents who made contact with me willing to be involved in this research. Throughout the interviews and now being able to reflect on the parents stories I understand that these parents are not just participants in a study but they are the body and soul of this research, without them, their experiences, and their courage and generosity this research would not be possible. Throughout this research the goal of simply adding to the academic body of knowledge was not enough, whilst I needed to add to the academic body of knowledge, I had to do so in a way that respected what had been given to me and use it in a way that honoured the parents and their babies. Undertaking qualitative research taught me the significance of the people's perspective and the great value of their combined stories and experiences. Not only do they add to research but they inform guidelines and policies that largely benefit those who follow in their footsteps. As Remen said 'Telling stories can be healing. We all have within us access to a greater wisdom, and we may not even know that until we speak out loud. Listening to stories can also be healing. A deep

trust of life often emerges when you listen to other people's stories. You realise you're not alone; you're travelling in wonderful company. Ordinary people living ordinary lives often are heroes.' (Remen, 1996, xviii). Just as I have learned a lot from the parents stories of this research I hope for those who read this research that you learn just as much. Whether you are a researcher, a bureaucrat, a healthcare professional, or the parent of a stillborn baby yourself I hope that the stories shared on these pages will in some way help those who go through a stillbirth in the future.

Final Thoughts

The experience for parents of finding out that their new baby, who they have waited, planned and prepared for, is dead is one of the most traumatising events that could occur in a person's life. The unexpected death of a person is upsetting but the unexpected death of a baby who has had no life at all can sometimes seem more traumatising and more difficult to cope with as it rejects the basic ideas and expectations of life (Rosenblatt, 2002). Parents who are awaiting the birth of their baby have full trust that the baby will be born alive and, for most parents, the fact that it is possible that their baby could die would never even cross their minds, especially in the current health climate where medicine and science can save some of the most premature babies. The silence that comes with the birth of a stillborn baby is devastating for parents who would give anything for their baby to take a breath.

This research tells the stories of these parents and their experiences in an aim to understand the care that they received and their perception of what is important during and after a stillbirth. Throughout the stories, many parents referred to the experience of having a stillborn baby as traumatising and the grief as overwhelming. For these parents, many are too devastated by the death of their baby that they are unable to take control of the situation and think and process information that would be helpful to them. Therefore, it is important that the healthcare professionals who care for these parents are fully aware of how critical it is that these parents are cared for well, as Downe, Schmidt, Kingdon, & Heazell (2013) stated 'everyone involved only one chance to get it right' (p.7). This means providing care that is empathic, understanding, informative, communicative, repetitive, personal, private, and supportive, it means not only looking out for the interests of the parent at the present time but also anticipating what they might need in the future. The story of each parent in this study was unique; however, there were commonalities between them and aspects that could be used to improve care for parents of stillborn children in the future.

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Appendices

Appendix One



HUMAN ETHICS COMMITTEE

Secretary, Lynda Griffioen
Email: human-ethics@canterbury.ac.nz

Ref: HEC 2015/105

12 October 2015

Georgia Millar
School of Health Sciences
UNIVERSITY OF CANTERBURY

Dear Georgia

The Human Ethics Committee advises that your research proposal "A qualitative study of the experience of parents who have stillborn children in New Zealand" has been considered and approved.

Please note that this approval is subject to the incorporation of the amendments you have provided in your email of 9 October 2015.

Best wishes for your project.

Yours sincerely

A handwritten signature in black ink, appearing to read 'L. MacDonald'.

Lindsey MacDonald
Chair
University of Canterbury Human Ethics Committee

Appendix two

School of Health Sciences

Telephone: 027 253 1377

Email: georgia.millar@pg.canterbury.ac.nz



A Qualitative Study of the Experience of Parents who have had a Stillborn Child in New Zealand

Information Sheet for Participants

I am a student entering into the last year of my Child and Family Psychology Masters Degree. I am undertaking a research project with the purpose of understanding the experience of parents who have had a stillborn child within New Zealand. The interviews will allow parents to share their stories and experiences of stillbirth in a way that will allow me to discover themes/insights that will provide health professionals and support agencies with ways to improve practice, lessen negative outcomes, and allow good practice to be acknowledged and continued.

Your involvement in this project is voluntary and will require you to be interviewed by the researcher who will ask you about your experience about having a stillborn birth. The interviews will be recorded to ensure the highest standard of authenticity. The time required for the interview will be variable depending on the length and detail of answers but it is estimated that each interview should take no longer than two hours. There will be no further requirements of you, as a participant, following the interviews.

During the interview there are risks of emotional distress. Stillbirth is a sensitive topic and the process of recounting personal experiences may revive some grief. Although talking about the loss and grief of losing a child can be extremely helpful in the process of moving forward, reliving those experiences is also likely to cause some emotional distress. Because of this, you will not be rushed during the interview process and you will have as long as needed to tell your story and experience. There may be times where you need a break, I will respect that and allow you a moment to breathe and bring yourself back to centre, during this time the audio recorder may be turned off if you wish. If you feel unable to continue with the interview, you have the option to suspend the interview and reschedule it for another day or you have the option to withdraw completely from the study. If, after the interview, you are still clearly upset, I will not leave until you are feeling more stable and if need be I will call a friend or family member to come and be with you.

You are entitled to receive a copy of the transcript to check that it is a true record of the interview and at this time you will be able to offer comment or correct if there are aspects you would like to alter or withdraw. You are also entitled to a copy of the research results.

Participation is voluntary and you have the right to withdraw at any stage without penalty. If you withdraw, I will remove all information relating to you up until the point of analysis.

The results of the project may be published, but you may be assured of the complete confidentiality of data gathered in this investigation: your identity will not be made public. To ensure anonymity and confidentiality all information with your name and other personal details (such as your consent form) will be kept separate from any data that you give. All data that you supply will use a code to identify it instead of your name. The only people who will have access to the data are myself, my supervisor and transcriber, and the transcriber will sign a Transcriber Confidentiality Agreement. All data will be stored securely either on password protected computers or in a locked filing cabinet in a locked room. All data will be kept for five years and then destroyed after that. A thesis is a public document and will be available through the University of Canterbury Library.

The project is being carried out as a requirement for a Masters in Child and Family Psychology by Georgia Millar, under the supervision of Kate Reid and Sarah Whitcombe-Dobbs; they can be contacted at georgia.millar@pg.canterbury.ac.nz, kate.reid@canterbury.ac.nz, and sarah.whitcombe-dobbs@canterbury.ac.nz. They will be pleased to discuss any concerns or queries you may have about participation in the project.

This project has been reviewed and approved by the University of Canterbury Human Ethics Committee, and participants should address any complaints to The Chair, Human Ethics Committee, University of Canterbury, Private Bag 4800, Christchurch (humanethics@canterbury.ac.nz).

If you agree to participate in the study, you are asked to complete the consent form and return via email to georgia.millar@pg.canterbury.ac.nz.

Georgia Millar

If you want to talk to someone who isn't involved with the study, you can contact an independent health and disability advocate on:

Phone: 0800 555 050
Fax: 0800 2 SUPPORT (0800 2787 7678)
Email: advocacy@hdc.org.nz

Or you can contact SANDS on:

Email: contact@sands.org.nz

Or you can find an email address and phone number for a contact person in your area on the SANDS Support Group Page.

Appendix three

School of Health Sciences

Telephone: 027 253 1377

Email: georgia.millar@pg.canterbury.ac.nz



A Qualitative Study of the Experience of Parents who have had a Stillborn Child in New Zealand

Consent Form for Participants

Please tick the box if you agree with the statement:

- ☐ I have been given a full explanation of this project and have had the opportunity to ask questions.
- ☐ I understand what is required of me if I agree to take part in the research.
- ☐ I understand that participation is voluntary and I may withdraw at any time without penalty. Withdrawal of participation will also include the withdrawal of any information I have provided should this remain practically achievable.
- ☐ I understand that any information I provide will be kept confidential to the researcher, the researcher's supervisor, and transcribers and that any published or reported results will not identify the participants.
- ☐ I understand that a thesis is a public document and will be available through the UC Library and may be published in other journals and disseminated throughout health professionals.
- ☐ I understand that all data collected for the study will be kept in locked and secure facilities and in password protected electronic form and will be destroyed after five years.
- ☐ I understand the risks associated with taking part and how they will be managed.
- ☐ I wish to receive a copy of the report at the conclusion of the project.
- ☐ I understand that I can contact the researcher, Georgia Millar (georgia.millar@pg.canterbury.ac.nz) or her supervisors Kate Reid (kate.reid@canterbury.ac.nz) and Sarah Whitcombe-Dobbs (sarah.whitcombe-dobbs@canterbury.ac.nz), for further information.
- ☐ If I have any complaints, I can contact the Chair of the University of Canterbury Human Ethics Committee, Private Bag 4800, Christchurch (humanethics@canterbury.ac.nz)

By signing below, I agree to participate in this research project.

Participants name _____

Date _____

Signature _____

Please return the consent form via email to georgia.millar@pg.canterbury.ac.nz within a week or bring the signed consent form with you to the interview.

Thank you for your consent.

Georgia Millar

Signature

A handwritten signature in black ink, appearing to read 'G. Millar', written over a horizontal line.